

**Understanding the effect of a participatory intervention with women's  
groups to improve maternal and neonatal health in rural Nepal**

Joanna Morrison

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University College London

Centre for International Health and Development

Institute of Child Health

University College London

I, Joanna Morrison confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

## Abstract

**Background:** Rigorous evaluation of community based interventions is necessary to build the evidence base for maternal and child survival in developing countries. Randomised controlled trials may be the most reliable method of determining effectiveness of interventions, but they are unable to evaluate the impact of context and implementation, and explain how an outcome occurred. This thesis explores the outcome of a cluster randomised controlled trial using women's groups in Nepal. Intervention areas experienced a 30% reduction in neonatal mortality, and increases in good care behaviours. I describe how communities experienced the intervention and explore how the implementation process and community context affected the community response.

**Methods:** I used qualitative research methods, purposefully sampling stakeholders from two intervention areas, and one control area. Photoelicitation was used, and research assistants conducted semi-structured interviews, group interviews, focus group discussions, and observations. Data were tape recorded, transcribed and translated into English. Data were analysed using framework and NVIVO qualitative analysis software. Data were also fed back to respondents to increase validity.

**Results:** Themes emerging from the data revealed a lack of trust in local health facilities, plurality in care seeking during illness, and a positive attitude towards working with non governmental organisations. Women's groups created a learning forum for group members, and this knowledge was disseminated in communities. Strategies to address problems were of particular significance in enabling dissemination of information and enabling community participation. The intervention increased social networks and built community capacity.

**Discussion:** The effect of context on the intervention is considered in order to assess the generalisability of the intervention. Potential mechanisms of effect are also discussed which help to explain the trial outcome. This thesis supports calls for the integration of concurrent process evaluations within randomised controlled trials, and contributes to the evidence for community-based interventions for maternal and newborn survival.



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### **Abbreviations used in the thesis**

ARI	Acute Respiratory Infection Programme
BCC	Behaviour Change Communication
BSA	British Sociological Association
CL	Community leader
DDC	District Development Committee
DHS	Demographic Health Survey
DPHO	District public health office
ENC	Essential Newborn Care
EPI	Expanded programme on immunisation
F	Facilitator
FCHV	Female community health volunteer
FFF	Food supplementation, family planning, female education (UNICEF)
FGD	Focus group discussion
GOBI	Growth monitoring, oral rehydration, breastfeeding, immunisation (UNICEF)
Group int	Group interview
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
HV	Health volunteer (FCHV and TBA)
HW	Health worker (VHW or MCHW)
I	Interview
ICH	Institute of Child Health
INGO	International non governmental organisation
LBW	Low birth weight
M	Men
MCHW	Maternal and child health worker
MDG	Millennium Development Goal
MIL	Mother in law
MIRA	Mother Infant Research Activities (implementing non governmental organisation)
MWRA	Married woman of reproductive age (between the ages of 15 and 49)
MMR	Maternal mortality ratio
MNPI	Maternal and neonatal programme effort index
NFHS	Nepal family health survey
NGO	Non governmental organisation
NMR	Neonatal mortality rate
ORS	Oral Rehydration Solution
PHC	Primary Health Care
PRA	Participatory Rural Appraisal
RCT	Randomised controlled trial
RRA	Rapid Rural Appraisal

SLC	School Leaving Certificate
TBA	Traditional Birth Attendant (as identified by the Ministry of Health, Government of Nepal)
UN	United Nations
UNICEF	United Nations Children's Fund
UNFPA	United Nations Fund Population Fund
USD	United States Dollars
VDC	Village Development Committee
VDCi	Village Development interviewer
VHW	Village health worker
WE	Ward enumerator (pregnancy monitor)
WG	Women's group (facilitated by MIRA)
WHO	World Health Organisation

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# **1 Introduction**

## **1.1 Scope of the thesis**

The randomised controlled trial (RCT) is widely recognised as the most rigorous way of evaluating the effectiveness of interventions. In recent years, there have been calls for the use of RCTs to evaluate complex social or public health interventions. These calls have been accompanied by advocacy for the use of an emerging methodology that can help to address the shortcomings of the RCT: process evaluation.

Around the same time, improvements in maternal and child survival in developing countries have been identified as a key development goal. There have been increasing calls for evidence of effective, sustainable, scaleable interventions, to address the needs of the poorest families. There have been few community effectiveness trials, and even fewer trials of complex participatory interventions.

This thesis uses a qualitative methodology to help policy makers, programme implementers and researchers understand the results of an RCT of a participatory intervention using women's groups in rural Nepal. Birth outcomes were significantly improved in intervention areas, as were uptake of services and practice of hygienic care behaviours. The trial results have provoked global debate, and agencies and policy makers have been keen to understand how this significant reduction in mortality occurred. This thesis describes research carried out between 2003 and 2008 in Makwanpur District, Nepal, to explore the mechanisms of effect, and contextual factors that may have affected the trial result.

## **1.2 Role of the investigator**

This research was conducted while I was in full time employment as a research fellow and technical advisor to the randomised controlled trial that this thesis evaluates. I took paid and unpaid leave and used my spare time to collect data and write-up this thesis. I lived in Makwanpur District headquarters of Hetauda from 2002-2008, with a Nepali family (of Newari ethnicity) and I learned to speak Nepali. I was based in the District office of the implementing non-governmental organisation (MIRA - Mother Infant Research Activities). Hetauda is around five hours drive from the capital city of Kathmandu and has a population of 79,860 (Sharma et al., 2007).

In my capacity as technical advisor, I have spent substantial time in the communities where the intervention was implemented and I have attended many women's group meetings. I have advised and participated in staff recruitment, training, and ongoing support of field employees in the field and in the District office. I started work with the project during the implementation phase of the women's group intervention. The intervention had been running for two years prior to my involvement. I worked collaboratively with the research team to develop the intervention during and after the trial period. I designed women's group manuals, and advised on the collection and management of process data from the women's groups. I designed research protocols to examine specific aspects of the intervention, I supervised the collection of data, and I led the write-up and publication of this data. In my working capacity and in my capacity as a PhD student, I have stayed with families in villages, and had informal conversations with men and women who live in the study area. I have developed personal friendships with many field employees, whose families have lived in the study area for generations. I have a depth of knowledge about the



intervention and the context that could only come from my level of involvement, and although this data was not recorded systematically, it has been included to present a fuller account of the women's group intervention. Publications of process data are also included in the appendices.

Unfortunately I was unable to conduct long-term participant observation in the field because of my employment responsibilities, and the unstable security situation. This research was conducted during a period of civil war in Nepal, and my access to the field was limited for my own safety and the safety of women's group and community members, many of whom were employed by the project and lived in fear and intimidation every day. Insurgents were suspicious of outsiders for fear of their activities being reported to the army and police. They may also have made unreasonable demands of financial support from MIRA employees, as a 'white face' indicates a well-funded project. In addition, insurgents were ideologically opposed to American and British citizens for their military support to the Nepali government.

I was also unable to observe any births in the District. It is considered bad luck for an unmarried woman to be present during childbirth, and there were logistical difficulties of the remoteness of villages, and the unpredictability of childbirth. I also had ethical concerns as I would not be able to build a relationship with the woman or the family (due to time constraints and employment commitments), and child birth is a private event where women and their newborns are thought to be particularly vulnerable, and usually contact with outsiders is minimal during this time. I was also concerned that the family may

believe me to be trained in delivery care, and I would be unable to provide timely access to life saving interventions if I attended a delivery.

Ideologically, I have a commitment to partnership working, and I believe that participatory approaches are often the best way to work with communities for lasting change. I describe how my roles as research fellow, technical advisor, and PhD student may have affected the research process in Chapter 8. I also describe how any potential negative effects, or bias, due to my role as research fellow and advisor were minimised.

### **1.3 Structure of the thesis**

This thesis begins with a literature review of approaches to research and evaluation, and considers different ontological and epistemological approaches. The role of process evaluation research in outcome evaluations is then discussed, and the challenges to integrating process evaluation data with outcome data are introduced.

The international maternal and newborn survival literature is reviewed in chapter 3, describing the global problem, and the situation in Nepal. Current research debates and research gaps are described and discussed.

This is followed by an introduction to Nepal in chapter 4, focusing on demographic, economic, and cultural information. Country specific issues about maternal and newborn health are discussed, and current interventions described.

Primary health care and participatory approaches are discussed in chapter 5, describing the theory that informed the intervention, and the difficulties with taking this kind of approach. Thereafter, the MIRA Makwanpur project is described, the results of the trial are presented, and the rationale for this thesis is stated.

The methods of this thesis are described in Chapter 6 and results of the themes emerging from the data are described in Chapter 7. The limitations of this study are discussed in Chapter 8, before an interpretation is made of how the context may have affected response to the intervention. The mechanisms that help further an understanding of how the intervention appeared to reduced neonatal mortality and increased care seeking behaviour is then explored. Chapter 9 describes recommendations for future research and conclusions.

## 2 Research and Evaluation

**Figure 1** Nepali researchers

Photograph by author



## **2.1 What affects choice of evaluation method?**

Many factors can influence how an intervention or programme is evaluated; concerns about time, money, skills, fears about future funding sources, commitment to research rigor, complexity of interventions, personal experience and audience consideration. Some would argue that pragmatic and technical considerations are more likely to influence choice of method, particularly in health research, but many researchers feel that research is most often theoretically driven (Pope and Mays, 1996). This section briefly introduces five different ontological perspectives and then describes the qualitative approach to evaluation. This discussion is followed by a description and critique of the experimental approach to evaluation. An approach to evaluation that uses mixed methods and draws on different epistemologies is then discussed (process evaluation). CINAHL, EMBASE, AMED, GEOBASE and Medline were systematically searched using terms ‘process evaluation AND randomised AND controlled AND trial’; ‘randomised AND controlled AND trial AND community’; ‘randomised AND controlled AND trial AND (maternal OR neonatal) (18.10.07). Other references were found by examining references of relevant literature, and through personal communication with colleagues and academics.

## **2.2 Theoretical perspectives**

Ontological and epistemological assumptions (assumptions about theories of being and about the nature of knowledge, and validity of knowledge) affect opinions on how to evaluate, and what methodologies are considered to be the most appropriate. These assumptions or perspectives provide a framework for thinking about the social world and inform the type of research design chosen, and interpretations of the research results. Much

of the debates regarding the value of research findings come from epistemological differences between researchers about what kind of knowledge they believe research should produce, or what counts as adequate evidence for conclusions to be drawn (Green and Thorogood, 2005) . The main epistemological approaches are positivist or post positivist, social constructivist, participatory and advocacy, pragmatic and realist (Creswell, 2003).

### ***2.2.1 Positivism and post positivism***

The positivist approach consists of a belief that there is a single reality, independent of any observer, and a belief that a universal truth exists, independent of time or place, and that this truth can be discovered (Green and Thorogood, 2005). Post positivists recognise that it is difficult to be positive about claims of knowledge, as humans are reflexive and it is not possible to create perfectly controlled environments for studying social phenomena. At present, some authors hold that few quantitative researchers would accept the charge that they try to produce a ‘science of laws’, instead, they would prefer to say that they seek to produce a set of cumulative generalisations based on the critical sifting of data (Green and Thorogood, 2005, Silverman, 2006). Post positivism preserves basic assumptions of positivism: ontological realism, possibility of objective truth and use of experimental methodology. It is concerned with the establishment of relationships of cause and effect. Post positivists believe that phenomena should be investigated in an objective manner, and believe that bias or subjectivity signifies weak validity and reliability – the truth of findings is questionable and their replicability are compromised. Favoured methods are experimental designs testing hypotheses, and research is concerned with predication through proof or certainty with simplified measures of reality and truth. The randomised controlled trial is a method favoured by post- positivists because it has high probability to

test the falsification of a hypothesis. The founder of positivism, Karl Popper, argued that scientific theories are only hypotheses and may be falsified and replaced, therefore what is important for the growth of science is not the confirmation but the attempted falsification of theories (Soydan, 2007). The randomised controlled trial is considered to be the most reliable form of scientific evidence, particularly in medical research.

### ***2.2.2 Social constructivist approach***

The constructivist approach is different from post positivism in several significant ways. Truth, reality and fact are considered to have subjective dimensions, and be socially constructed (Green and Thorogood, 2005). Experiences are located in a particular socio-historical context, and therefore there is no single universal truth, but multiple truths based in experience and context. Realities are local and specific, dependent on their form and content and on the persons that hold them (Patton, 2002b). Truths can be shared by those of similar experience or characteristics. Favoured methods seek to elicit, refine, compare and contrast individual constructions with the aim of generating one or more constructions on which there is substantial consensus (Laverack, 2007). Truth is not absolute but is understood as the best-informed and most sophisticated truth we might construct at any given moment. The researcher is recognised as an active participant in the construction of truth, and their truth and experiences should be acknowledged (Green and Thorogood, 2005). The objective of research is to find out how phenomena are constructed and inductively develop a theory or pattern of meaning, and qualitative methods are usually used.

### ***2.2.3 Participatory/advocacy approach***

The participatory/advocacy approach is a type of social constructionist research.

Researchers who developed this approach believed that research should be combined with politics and a political agenda. They believed that constructivism did not go far enough in advocating for an action agenda to help marginalised groups (Creswell, 1998, Gaventa and Cornwall, 2001). The focus of the research is often the oppression or inequality suffered by marginalised groups, and research seeks to emancipate, and work collaboratively with participants to avoid further marginalisation (Lewis, 2001). Feminist approaches are an example under the heading of participatory/advocacy approach (Maguire, 1987).

Researchers taking this approach believe that the worldview, or reality, put forward is a masculine reality, and research acknowledges the fundamentally different perspectives of men and women. This approach to research seeks to give voice to participants, and advance an agenda or action to change the situation of marginalised populations. Research following this epistemology often takes a participatory action oriented approach.

Participatory action research emphasises mutual learning of all stakeholders to address a problem. This mutual learning galvanises participants to plan and implement a plan of action in order to change their social situation and address the problem (Reason and Bradbury, 2006, Baum, 2006).

### ***2.2.4 Pragmatism and realism***

Pragmatism is similar to realism in that there is agreement on the importance of considering research occurring in a social historical context, and there is a rejection of positivism.

These traditions developed from the constructionist approach, but advocates of pragmatism



feel that constructivism suffers from an inability to grasp structural and institutional features of society, which are in some respect independent of reasoning and desires (Pawson and Tilley, 1997). Both traditions also have a pluralist approach to methods, using different methods to understand a problem, depending on which mix is the most appropriate. There are two main areas of difference between pragmatism and realism, the attention to reality, and the focus on consequences of research (Cherryholmes, 1992). Pragmatists are more concerned with constructing research so that it can be better used in the processes of policy making. There has been a shift from a knowledge-driven to a use-led model of research (Weiss, 1976, Weiss, 1990, Pawson and Tilley, 1997). The focus of research is not on staying true to a world view, but to produce research that enables policy making and provides the best understanding of a research problem (Patton, 1990). While realists search for realities, pragmatists question the ability of any tradition to find 'reality' (Cherryholmes, 1992). Realists hope to find out underlying causal entities by empirically testing different propositions. They believe that causal outcomes follow from mechanisms acting (or not acting) in contexts (Pawson and Tilley, 1997). On the other hand, pragmatists focus more on consequences, choosing what to research, and how to research, by beginning with what they think is known, and projecting desirable consequences (Cherryholmes, 1992).

### **2.3 Qualitative research**

Most qualitative research rejects a positivist epistemology and adopts constructionist or participatory/advocacy approaches. Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem (Creswell, 1998). Qualitative researchers build a complex holistic picture, analyse words, and report detailed views of informants. Qualitative research is usually

conducted in a natural setting and researchers try to answer research questions of what, how and why. It is better suited to answering questions that are not located in positivist epistemologies (Creswell, 1998). Qualitative research has its roots in early ethnography and colonial ethnography, when initially the researcher produced objective, colonising accounts of field experiences that were reflective of the positivist perspective (Denzin and Lincoln, 2000). Since then, qualitative research has evolved and entered into many other academic disciplines.

Qualitative research has been slower to gain credibility and widespread use in the health sector, as practitioners accustomed to 'definitive' answers and numerical 'facts' have struggled to understand and interpret qualitative research. However, there is a growing realisation among the medical profession that qualitative research can answer questions that other methods cannot (Pope and Mays, 1995). Instead of counting who experiences a health problem, or counting its incidence, qualitative research asks, "what is the health problem?" and "how is it experienced by practitioners and patients?" Quantitative research methods represent a confined access to clinical knowing, as they only incorporate questions and phenomena that can be controlled, measured and counted (Malterud, 2001b). Qualitative enquiry can perhaps contribute to a broader understanding of medical science, and clinical work may benefit from a range of different types of evidence (Malterud, 2001b).

Qualitative research is not a single monolithic approach to research and evaluation, and has developed over time. Denzin and Lincoln describe six phases in the development of qualitative methods, and anticipate its further development (Denzin and Lincoln, 2000). Patton feels that there is no definitive way to categorise the various philosophical and

theoretical perspectives that influence and distinguish types of qualitative enquiry (Patton, 2002b). Creswell finds that researchers can have a baffling number of choices of traditions, and chooses to write about five traditions (biography, phenomenology, grounded theory, ethnography, and case study) that are popular and frequently used (Creswell, 1998).

### ***2.3.1 Shared orientations***

Although qualitative research is not a single monolithic approach to research, there are broad orientations to the methodology that are shared across different approaches. Green and Thorogood present three broad orientations that are shared by researchers and that distinguish the qualitative approach: a commitment to naturalism, a focus on understanding, and a flexible approach to research strategy (Green and Thorogood, 2005).

#### ***2.3.1.1 Naturalism***

Qualitative researchers prefer to study a phenomenon or people in their natural setting. They believe that behaviours and responses are context specific, that people actively construct their worlds but not completely on or in their own terms.

Therefore it is important to study experiences or behaviours where they occur. The researcher does not attempt to manipulate behaviour, but instead tries to ‘blend in’ and watch the phenomenon unfold naturally in the real world. The researcher tries not to influence those being researched, although this is difficult to achieve, and seeks to build rapport and credibility with the individuals in the study. Considerable time is spent in the field gathering information, trying to gain as deep an understanding of a situation or

experience as possible. Observations can be made, and open-ended interviews are conducted in a conversation-like way in a place of familiarity and comfort to the respondent (Patton, 2002b).

#### *2.3.1.2 Focus on meaning and understanding*

Qualitative research is defined by its concern with the meaning people attach to their experiences of the social world and how people make sense of that world (Pope and Mays, 1996). Qualitative researchers try to interpret social phenomena in terms of the meanings that people bring to them. Researchers take nothing for granted, asking fundamental and searching questions about the nature of social phenomena, and trying to know and understand the perspective of those being researched. It is important that qualitative researchers must empathise with respondents to focus on exploring the rationality of their behaviour (Green and Thorogood, 2005). Researchers must have an acceptance of simultaneous multiple world views, and be conscious of their own world view. Qualitative researchers should describe and explain their social, philosophical and physical location in the study, honestly probing their own bias.

#### *2.3.1.3 Flexible research approach*

Although qualitative studies need careful planning, there should be a degree of flexibility in order to explore an issue further or sample more broadly to meet the demands of a research project. Qualitative research is an emergent approach rather than tightly prefigured (Creswell, 2003). As the research develops it informs the research design, which can be adapted as data are collected and analysed. It is likely that when more is known about a phenomenon, a slightly different line of enquiry may be necessary, perhaps requiring

different methods. In quantitative research, there is emphasis on standardisation of instruments and tools, whereas in qualitative research it is usual to use multiple methods and be flexible and open to new ideas and methods. Again, the subjective nature of enquiry is emphasised, as the researcher becomes the research instrument, making deliberate decisions about ideas generated and reconfirmed on the one hand and intuitive reactions on the other (Janesick, 2001).

#### *2.3.1.4 Reflexivity*

Qualitative research has been criticised for its lack of objectivity. Yet qualitative researchers tend to have the perspective that *all* research is subjective, or value laden, and dispute the idea of researcher as neutral observer (Malterud, 2001a). Instead of focussing on ways to eliminate bias, some qualitative researchers acknowledge subjectivity, and throughout the research process, personally reflect on how they may be influencing the research design, data collection, analysis and interpretation. Some qualitative researchers systematically reflect on who they are in the inquiry process and openly report personal bias, experience, values and interests (Creswell, 2003).

#### *2.3.1.5 Sampling*

Methods of sampling are partly determined by the purpose of the qualitative research and its generalisability, or external validity. Some qualitative researchers find questions of generalisability irrelevant (Guba and Lincoln, 1985), and hold that this is an evaluation criterion relevant only to quantitative work. Others wish to generate theory that can be transferable, and produce information that can be shared and applied beyond the study setting (Pope and Mays, 1996). To do this, there has to be a level of abstraction, or

separation, between the theory and the data in which it is grounded which some researchers think weakens the interpretation: what is gained in generalisability, is sacrificed in context and detail (Johnson, 1997). Some researchers are more focussed on producing descriptions, notions or theories that are applicable within a specified setting (Malterud, 2001a). In this case, qualitative researchers need to give a 'thick description' detailing the study context in order for other researchers or programme implementers to assess the transferability, or external validity, of the study.

Qualitative research seeks to generate theory or describe experience, as opposed to generalise from a sample to the population, and therefore sampling methods are rarely random or large (as in probability sampling for quantitative research), and are usually purposive or theoretical. These forms of sampling select information rich respondents, strategically and purposively, in order to help the researcher answer the research question. Previous experience, literature review and theoretical frameworks will indicate whom to approach. The number of respondents sampled depends largely on feasibility, the question of study, considering what will be useful, and what will have credibility (Morse, 2000). If a researcher was trying to understand variation in a phenomenon, then a slightly larger sample may be needed (although not as large as for probability sampling) but usually smaller sample sizes of information rich respondents yield sufficient information to interpret and triangulate (see section on validity and relevance below).

There are many different strategies of purposive sampling (Patton, 2002b). The type of research study undertaken may affect the type of sampling used, as certain types of sampling are useful for particular approaches. For example grounded theory uses

theoretical sampling as is described above, it may be necessary to consider the users of the research, and state that the sample must be ‘credible’ to them (Green and Thorogood, 2005). This may involve choosing respondents that are ‘representative’ of a range of different experiences, or different types of people. Purposive samples are often generated on the basis of theories about who will be ‘information rich’ in that particular context, and who is likely to hold different perspectives in that context. Often sampling is opportunistic, or convenient, when there are constraints of lack of respondents, time, place etc. A more rigorous approach may be to combine purposive and convenience sampling if necessary.

## **2.4 Randomised controlled trials**

Randomised controlled trials (RCTs) are designed to test the efficacy of an intervention (drug, treatment, or programme), through randomly allocating subjects or clusters to receive the intervention or to act as controls. Subjects or clusters can be matched before allocation. Trials may be open (everyone knows who is receiving the intervention), blind (subjects do not know who is receiving the intervention), or double blind (researchers nor subjects know who is receiving the intervention). Subjects or clusters are then monitored over time.

### ***2.4.1 Why evaluate with a randomised controlled trial?***

The randomised controlled trial method comes from agricultural experiments in the 1920s, and in 1946 this method was used to test a drug to treat tuberculosis. This method gained legitimacy in medicine because of an increasing realisation that the medical profession needed to be regulated, and that medicine should be evidence based (Hearn et al., 2003). In

the natural sciences, the randomised controlled trial has become significant as the gold standard of evaluation, the ideal to which all research designs should aspire. With the move to evidence based medicine, the Cochrane review system was developed, and the effectiveness of new biological products had to be proven through randomised controlled trial before licensing (Hayes, 2003). Research based policy making, and research informed decision making became attractive in all sectors in the 1960s (Oakley, 2006). Randomised controlled trials, and cluster randomised controlled trials have had major influences on policy, cementing their reputation as the gold standard for testing efficacy of interventions (Van de Ven and Aggleton, 1999). The randomised controlled trial is considered to be the most reliable form of scientific evidence because the process of randomisation is the best method for eliminating factors, both known and unknown, that might cause differences between the intervention and control groups. Elimination of confounding variables means that any differences observed between the intervention and control groups are very likely to be caused by the intervention. The RCT also overcomes the Hawthorne effect, whereby there is a possibility that participant's can be affected by the research just by participating (i.e. sometimes participants may react to the attention on the subject of research). RCTs overcome this issue by equally monitoring intervention and control clusters or subjects. RCTs have strong outcome measures, because they test a hypothesis, and they are usually undertaken with careful attention to research design and rigour. Guidelines have been standardised to assess their quality, enabling researchers to follow rules in the design and write up of their results (The consort group, accessed 21.08.08). In a well-designed and implemented RCT, there is consistency in measurement, clarity, and consistency of method. They are designed to be generalisable to populations and there is comparability of outcomes between treatment and control groups. Cluster RCTs can be conducted where



interventions are hypothesised to impact on communities, but it is more difficult to eliminate confounding variables in a cluster RCT because there may be significant intra-cluster correlation that cannot be eliminated by randomisation. RCTs are considered a reliable method for reducing or eliminating bias and the best method for adding to the understanding of medical conditions and treatments. They are strongly related to a post-positivist approach. There is widespread opinion in the health care profession that it is unethical to implement large scale healthcare interventions without rigorous RCT evidence (Crump, 2008).

## ***2.4.2 Why not evaluate with a randomised controlled trial?***

### ***2.4.2.1 Feasibility and appropriateness***

RCTs have their limitations, and researchers who disagree with the positivist or post-positivist approach to research are among its strongest critics. They fear that the overwhelming shift to the experimental approach has prevented researchers from finding ways to address the shortcomings of the RCT, and using the experimental approach alone is limiting our understanding of health problems and their solutions (Hearn et al., 2003). The prioritisation of experimental RCTs has downgraded observational studies, and therefore the benefits of using these methods are being forgotten (Tones, 1997, Britton et al., 1998, Van de Ven and Aggleton, 1999, Rychetnick et al., 2002, Pawson and Tilley, 1997). Some authors feel that the shortcomings of the RCT are overlooked because of its prominence as the gold standard (Rychetnick et al., 2002). This bias towards the RCT has affected funding applications, and in academia, success is measured by funding applications and publication (White, 1997). Researchers are motivated to use this method when it may not be the most appropriate, and may tend to research issues that are amenable to this approach

(Van de Ven and Aggleton, 1999, Thomson et al., 2004). Other authors also hold that some populations and some studies do not lend themselves to experimental evaluation. For example some argue that ‘well being’ is difficult to quantify. This can skew research topics, and can also skew the type of populations participating in experimental studies, making the participants in RCTs not representative (Van de Ven and Aggleton, 1999, Britton et al., 1998).

Random allocation and blinding is sometimes not feasible (Bonell et al., 2006a), and some authors assert that it is unethical to randomly assign patients (Pedroni, 2006), while many argue that randomisation is only ethical when there is genuine uncertainty about which treatment to offer (Stephenson et al., 2003). Some authors question the closed nature of findings (blinding), and feel that patients should be provided with interim results and be able to choose whether they wish to stay in their chosen group (Pedroni, 2006). RCTs are also criticised for their disempowering nature, and some argue that it is important for studies and outcome measures to be relevant and meaningful to participants (Dzewaltowski et al., 2004, Butterfoss, 2006, Roberts, 2004, Thurston and Potvin, 2003). Participatory action research approaches that give primacy to learning rather than ‘proving’ are, for some, more appropriate in evaluation of health promotion (Springett, 2001).

#### *2.4.2.2 Bias in self reported behaviours*

Attitudinal and behavioural measures can be prone to bias in an experimental study, with respondents intentionally (through underreporting undesirable behaviours) or unintentionally (through misinterpretation of questions) providing inaccurate responses (Van de Ven and Aggleton, 1999, Oakley et al., 2004, Cowan and Plummer, 2003).

Bhandari was concerned about overly positive reporting in her study about the impact of breastfeeding on diarrhoeal illness (Bhandari et al., 2003b), while Van de Ven and Aggleton argue that undesirable behaviours are underreported in research about sexual health (Van de Ven and Aggleton, 1999).

#### *2.4.2.3 Contamination and cost*

Another difficulty of using the RCT to evaluate community based health promotion interventions is that contamination may be difficult to avoid. Health promotion messages may also affect the control areas (Susser, 1995, Tones, 1997, Bonell and Imrie, 2001). ‘Buffer’ zones can be used, but there are few limitations to human mobility. Some authors who feel RCTs are beneficial, maintain that RCTs should be conducted to the highest standards in order to justify the cost, time, and substantial skills required to conduct an RCT (Stephenson and Imrie, 1998, Hayes, 2003). Others feel that the expense and time and unfeasibility of RCTs in many contexts, mean they are often just not a pragmatic option (Tones, 1997).

#### *2.4.2.4 RCTs can't evaluate processes*

Some authors assert that evaluating at an artificial ‘end point’ is not useful when the intervention induces a process that may continue after the research has finished (Hearn et al., 2003, Britton et al., 1998, Susser, 1995). The very complexity of the social world means that complex interventions are often necessary and the standardisation of content and delivery mechanisms required by RCTs is difficult to maintain (White, 1997, Stephenson et al., 2003). The human volition factor also makes evaluating complex or multifaceted interventions with an RCT difficult, and the notion of cause is complex when it is applied

to social settings (Stephenson et al., 2003, Rychetnick et al., 2002, Oakley, 2004). Some authors question the usefulness of experimental research in social policy or health promotion as studies have largely led to negative or confusing findings. Some practitioners question their usefulness, as interventions may be being evaluated with the ‘wrong tools’ (Speller et al., 1997, Pawson and Tilley, 1997). The small or non-significant results of many community interventions may be due to the fact that interventions cannot compete with poverty and inequality to produce large impacts needed for statistical significance (Hawe et al., 2004b). Small effects on communities are not detected by RCTs, despite the fact that they may have a positive benefit at a population level (Roberts, 2004). Hearn agrees with Roberts, and is worried that the RCT approach does not provide adequate information on which to make policy decisions (Hearn et al., 2003). An ‘ineffective’ outcome evaluation may conceal the quality and value of the intervention to practitioners and patients. He argues that this data may be better revealed through qualitative research. In cases of small or non-significant results, authors suggest that the intervention may have been of insufficient dose, or insufficiently intense, or the number of communities could have been too few (low sample size) to gain statistical significance (Susser, 1995). Yet, those who favour experimental evaluation argue that findings of small or no effect support the view that an interventions’ efficacy should be evaluated with an RCT to prevent wasting money and potentially harming people (Oakley, 2004).

#### *2.4.2.5 RCTs only measure outcome*

For many authors, the main weakness of the RCT method is its sole focus on outcome. Experimental evaluation is not capable of asking the questions that evaluation must answer: how and why did an intervention work or fail to work? Researchers cannot interpret or

explain results of an RCT based on the outcome measure alone, which does little to help policy makers and programme implementers (Pawson and Tilley, 1997). Pawson and Tilley use examples from the crime prevention literature to illustrate that when policy makers are faced with unexplained or contradictory results, they find it difficult to make informed decisions. Wight and Obasi present a succinct critique of the RCT questioning its ability to help researchers understand how outcome results occurred, and what influenced the effectiveness of the intervention (Wight and Obasi, 2003) (Box 1).

**Box 1** What are the shortcomings of outcome evaluations (RCTs)?

1. Outcome studies of interventions that have been poorly designed and developed may influence those interpreting or reading a study to falsely assume that any intervention in this area would fail
2. Comparison of groups according to their initial allocation – this assumes that respondents have received an equal ‘dose’ of the intervention, and obscures any variation in implementation that may have occurred
3. Outcome evaluations do little to improve our understanding of how an intervention is supposed to work, and thus fail to inform the further development of effective interventions
4. An RCT of a complex programme with several components will not in itself allow one to distinguish which components were a success or failure
5. Outcome evaluations do not investigate the crucial contextual factors that might facilitate or prevent the success of an intervention: unless this is known it is difficult to ensure their adaptation or replication in other settings
6. Investigating the impact of an intervention in aggregate does not explore differential effects within the target group, or the control group. Yet, many programmes have heterogeneous effects and aggregation may obscure more than it reveals.

(Wight and Obasi, 2003)

Other authors have also criticised RCTs for these reasons (Pawson and Tilley, 1997, Van de Ven and Aggleton, 1999, Tones, 1997, Speller et al., 1997, Rychetnick et al., 2002). Linnan and Steckler add another important point to this critique: the theory base for the intervention is not presented routinely in RCTs, and therefore it is difficult to judge fidelity to this theory, or fidelity to initial implementation plans (Linnan and Steckler, 2002a).

## **2.5 Combining epistemological approaches**

Constructionists, realists, and participatory/advocacy researchers are united in their rejection of the positivist and post positivist approach of experimental evaluation. Yet recently there has been a growing body of social scientists taking a realist/pragmatist approach to evaluation. These researchers accept many of the criticisms made of the RCT (and often actively critique the method), but they believe that much can be gained from combining epistemological approaches. They believe that trials offer the most rigorous and pragmatic context in which to assess the outcomes associated with behavioural interventions. Oakley holds that social science is not in a healthy state, as it is too insular, and often confuses theory building with speculation (Oakley, 2006). She argues that definitions are often too arbitrary, and that subjectivity is too frequently extolled as superior to the delusion of scientific objectivity. Sheldon also criticises health promotion practitioners who base their practice on opinion, received wisdom or a favoured theory, occasionally supported by selective reference to a few studies of variable quality, which rarely assess health outcomes (Sheldon et al., 1998). Oakley accuses many social scientists of a lack of objectivity as assumptions of inherent goodness of interventions are often not evidence based (Oakley, 2006). With the exception of the USA, health promotion

interventions have tended to be evaluated in a non-experimental manner. For example, a systematic review of peer-led health promotion for young people found that only 30% reported process and outcome data, and only 38% reported outcome only data (Harden et al., 2001). Loevinsohn reported on a review of health education interventions in developing countries and found that only three articles used large samples and experimental designs to evaluate their effect (Loevinsohn, 1990). Some authors assert that it is important to evaluate the effectiveness of interventions and that it is unethical not to use the most objective methods available (Thomson et al., 2004, Oakley et al., 2006). Stephenson and Imrie argue that interventions that target behaviour are often demanding and costly and require highly skilled staff, therefore their efficacy should be tested before spending resources (Stephenson and Imrie, 1998). Without a control group, results are often difficult to interpret, and there is a danger of over-interpreting results if only process evaluations are used to evaluate (Oakley et al., 2004). Oakley feels that trials with process evaluations protect the public from potentially damaging uncontrolled experimentation and a more rational knowledge about the benefits of interventions is needed before they are applied to populations (Oakley, 1998). This bridging of epistemological approaches, bringing the RCT into social science, has inherent difficulties but authors challenge social scientists to try to overcome these difficulties.

### ***2.5.1 Randomisation and standardisation***

Although some argue that randomisation is often not possible, ethical, or feasible, others believe that randomisation is a good way to deal with the complexity of the nonlinear real world (Oakley et al., 2004). Hawe et al. also present a strong case that RCTs do not have to be standardised, they can be complex as communities are complex systems and health



problems or phenomena are recurrently produced by the system (Hawe et al., 2004a).

Therefore, in order to provide enough information to replicate trials, it is most important to report on what is standardised and what is context specific i.e. workshops could be standardised, but adapted to local contexts. RCTs can be designed in ways that overcome some of their other weaknesses: integrating 'process evaluations' in trials, combining qualitative and quantitative methods of data collection, completing thorough preparatory work, and stating the theory base of an intervention (Hearn et al., 2003, Oakley et al., 2006, Wight and Obasi, 2003, Stephenson and Imrie, 1998).

### ***2.5.2 Process evaluation***

Process evaluations can offer information on implementation, effect of context and help to explain the results of trials (Stephenson et al., 2003). Process evaluation has a relatively recent history, and was recognised formally in the 1970s (Oakley et al., 2004). Linnan and Steckler present a descriptive history of process evaluation from the 1960s, concluding that the USA has led research on experimental evaluation with process evaluation (Linnan and Steckler, 2002a). In the 1980s experimental studies of health promotion with process evaluations (to prevent heart disease and promote healthy living) received federal funding. The CATCH (Child and Adolescent Trial for Cardiovascular Health) study ran from 1986 to 1994 and is singled out by Linnan and Steckler as an extensive process evaluation that was key in the development of process evaluation theory and methods (Luepker et al., 1998, Perry, 1997, McGraw et al., 1994, Stone et al., 1994, Linnan and Steckler, 2002a). In the late 1990s and early 2000 there was an increase in the number of published studies that included extensive process evaluation components. Linnan and Steckler believe this is due to the fact that social and behavioural interventions have become increasingly complex and

there has been an increasing need to see how results were achieved (Linnan and Steckler, 2002a).

### ***2.5.3 Definition of process evaluation***

Due to the relatively recent development of process evaluation there are emerging (but not fully established) definitions for key process evaluation components. Process evaluation aims to describe the intervention factors that are key in understanding outcomes and the interactions between these factors. It considers: a) the context in which the intervention is delivered; b) the extent and quality of implementation of the intervention; c) the mechanism by which the intervention is assumed to work; and d) the differential responses of the target population. These data can be used to help explain and understand trial results, and can help generate hypotheses to be tested using outcome data. One of the most commonly cited process evaluations that have been used to inform policy making is Elford's process evaluation of a peer education programme to prevent the spread of HIV among gay men (Elford et al., 2001, Hart and Elford, 2003). The intervention had been tested in several cities in the USA and had shown positive and substantial reductions in risk behaviours among gay men (Kelly et al., 1997). The intervention was adapted to the local context and implemented in Glasgow, in London, and a 'control' city of Edinburgh. In both intervention cities there was no significant impact on gay men's sexual risk behaviours. Process evaluation conducted in both cities led to an explanation of the results of these trials. In London, a lack of diffusion impeded the intervention, with high attrition rates (due to lack of time, lack of interest, and lack of confidence), and peer educators found it difficult to discuss sex with strangers. In Glasgow, peer educators made substantial contact with the target community, but behaviour changes were not significant. Instead, the study

found that the peer educators facilitated access to sexual health services. The studies found that although peer education is supported by social theory (and intuition), in practice it is difficult to recruit, train, and support sufficient numbers of peer educators at the community level, and it is also costly, and probably ineffectual to do so.

#### ***2.5.4 New framework for evaluating trials***

Calls for the integration of process evaluation in RCTs, have led to some authors requesting for revised guidelines to judge the quality of RCTs (Dzewaltowski et al., 2004, Hawe et al., 2004a, Bonell et al., 2006b). Dzewaltowski et al. published a limited literature review of experimental and quasi experimental health promotion research articles about diet, physical activity, and smoking cessation (Dzewaltowski et al., 2004). They found that, overall, studies did not report sufficient information to judge representativeness of community based settings and populations, therefore the generalisability of the findings was largely unknown. Authors argue that trials should publish information allowing readers to assess the generalisability of findings, as well as their feasibility, the coverage of the intervention, and their acceptability. If trials only publish outcome data, the learning that can be gained is not maximised. If information on generalisability, feasibility, coverage and acceptability were provided, this would help the development of future research evaluating interventions. This culmination of evidence would enable readers to judge the suitability of the intervention in their context, as well as help explain the reasons for the trial result. Bonell et al. hold that if the effects of RCTs are to be generalised, there should be a framework for empirically assessing and reporting on RCTs – over and above the consort guidelines (Bonell et al., 2006a). Replication of trials in different settings is useful and trials should be judged in terms of their generalisability as well the design and methods that they used.

### ***2.5.5 Methodology of process evaluation***

Linnan and Steckler state that there is a lack of theoretical underpinning for process evaluation, yet the literature makes reference to an emerging realistic or theory based evaluation epistemology (Linnan and Steckler, 2002a).

#### ***2.5.5.1 Theory based process evaluation***

Many of those advocating for process evaluation argue that the mechanisms by which the intervention is assumed to work should be explored before the design of evaluation studies. Pawson and Tilley have a formula that they suggest researchers work through in theorising ways in which interventions may or should work (Pawson and Tilley, 1997). They suggest that theories can come from the literature, but can also be developed through interviews with practitioners, researchers and policy makers. They suggest building theories together with those experienced in the field, through feeding back theories for confirmation or refinement. These theories may enable planning for sub-group analysis of data. To illustrate, they use examples from the crime prevention literature, and present some of the theories behind a prison education initiative to prevent re-offending (Box 2). They also use an example of a successful crime prevention project (Kirkholt) to explain how to unpack the ‘black box’ of how an intervention worked or failed to work (Figure 2).

**Box 2** Theories about mechanisms of change in an education intervention to prevent re-offending of prisoners

<i>Education might be a spur to self-realisation.</i> Following a particular course might lead to inmates developing knowledge, skills and confidence which realise their potential for the first time
<i>Education might lead to economic potential.</i> Education of whatever sort can be considered to have a training element, which could act as a launch pad for providing different sorts of opportunities towards a new career.
<i>Education might promote social acceptability.</i> Education is a profoundly social activity, and the behaviour and skills learned therein might become routine ways of acting which will allow an inmate to function in a wider range of settings.
<i>Education might lead to moral or civic responsibility.</i> Certain curricula will involve discussion of law making, rule keeping, justice, rights and responsibilities, right and wrong. These might filter in and become part of the general mind-set of the (ex) offender.
<i>Education might lead to cognitive change.</i> Education is perhaps above all, about developing the reasoning process. In confronting a whole new range of ideas, perspectives and philosophies, the inmate's own power of reasoning and self reflection might be deepened, encouraging a new outlook on old problems.

(Pawson and Tilley, 1997)

**Figure 2 Unpacking the black box of how an intervention worked or failed to work**

Something about Kirkholt  (Context) (Pawson and Tilley, 1997)	+	Something about the project (Mechanism)	=	Dramatically reduced burglary rates (Outcome)
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Other authors take a less formulaic approach to theory building, but still advocate for theory based research and adequate description of context and mechanism (Bonell and Imrie, 2001, Harachi et al., 1999, Sutton, 2003, Nazareth, 2003, McLeroy et al., 2003). They feel that the concerns raised about conducting RCTs of complex interventions (cost, time, skills, ethics, difficulties of implementation) make it especially important to conduct an optimum RCT that is based on good piloting (with an integral process evaluation), formative work, as well as clearly stating the theory base of the intervention. Preparatory work is important in order to find the most feasible or relevant outcome measures and enable potential implementation problems to be ironed-out (Shain et al., 2003). Feasibility of conducting the trial can also be examined, testing the suitability of the methodology in that specific population (Bradley et al., 1999, Rychetnick et al., 2002, Grosskurth and Kumaranayake, 2003, Hawe et al., 2004b). Coleman and Ford, and Nazareth have published similar 'steps' that should be taken before the conduct of a 'definitive RCT' (Coleman and Ford, 1996, Nazareth, 2003). Researchers should 1) state the theoretical basis of the intervention 2) define the population, 3) define the intervention (including a hypothesised causal pathway reflected in choice of outcome measures) 4) conduct an exploratory trial - examining consistency of delivery and issues of staff burn out, checking for learning curve of implementers, checking for control issues, checking randomisation and sample size, recruitment levels, and acceptability of the intervention to the population. Coleman and Ford add that a post test intervention measure should also be taken after the intervention has been completed to look at sustainability issues and examine change over time (Coleman and Ford, 1996). Other authors feel that if piloting is not feasible, interventions can be implemented in a stepwise manner, thereby addressing ethical

concerns of control clusters not receiving benefits, and dealing with difficulties of implementation in subsequent ‘steps’ (Roberts, 2004, Bonell et al., 2006b, Campbell et al., 2007). Examples of preparatory work can be seen in publications by Rudolf et al., Charleston et al. and Bradley et al. (Rudolf et al., 2006, Charleston et al., 2002, Bradley et al., 1999). Hong describes problematic areas of an intervention – detected through a process evaluation - that were changed to improve their study of an HIV prevention programme among injecting drug users (Hong et al., 2005).

Defining the theory base of the intervention is not always easy, because health behaviour interventions are often multi theory based and designed to change several explanatory variables at the same time with the objective of maximising the intervention effect. Sutton argues that a theory of behaviour change can be embedded in a larger causal model, and it is useful to define the causal model and estimate effect sizes in designing and analysing interventions (Sutton, 2003). Wight and Obasi also argue that it is beneficial to develop causal pathways, and urge researchers to consider alternate hypotheses before conducting trials, to ensure that sample sizes are large enough so that sub-group analysis has sufficient power to detect statistically significant difference (Wight and Obasi, 2003).

#### ***2.5.6 Methods in process evaluation***

A realist approach tends not to favour particular methods of data collection, and sees merit in marrying the quantitative and qualitative so that both the processes and impact of interventions may be investigated (Pawson et al., 2005). Realists tend to reject the view of the RCT as the best method of evaluation (Pawson and Tilley, 1997). Linnan and Steckler feel that there is little information available to help guide decision-making on which

methods to use when conducting a process evaluation (Linnan and Steckler, 2002a). Since the publication of their book, a number of process evaluation studies have been published that give researchers some examples to draw on, although some of the detail is missing from publications. Unlike methodologies that use preferred methods to collect data (i.e. phenomenological research usually uses in-depth interviews), it appears that process evaluation methods of data collection are largely determined by the theories being explored, the research aims and objectives and practical constraints. Hartley et al's study about relationships between health authority commissioning and HIV health promotion needs among gay men sampled from three different categories of organisation, and developed separate methods of data collection for each group. These were a combination of questionnaires and in depth interviews (Hartley et al., 2000). Baranowski and Stables conducted a process evaluation of an RCT evaluating the efficacy of an intervention to increase fruit, juice and vegetable consumption for prevention of primary cancer (Baranowski and Stables, 2000). They used detailed observation checklists, rating scales, self-completed questionnaires, parent completed verification of home tasks, and other methods (that were not described) to collect data. They collected data from implementers, research staff, participants, family members of participants, and other respondents (that were also not described). They felt that their methods were not equally valid and did not create easily comparable data. They call for research rigor to be estimated in process evaluation methods. Gregson et al. report on an interim process evaluation of an RCT of an integrated community and clinic based HIV control programme (Gregson et al., 2007). They used an 'informal confidential voting interview method' to collect process data, and it is unclear how data was collected to measure 'process indicators (examining) changes in knowledge, psychosocial status and indicators of programme coverage and quality'. Other



examples include: (Linnan and Steckler, 2002b, Audrey et al., 2004, Singh et al., 2006, Oakley et al., 2006, Rudolf et al., 2006, Reynolds et al., 2000, Hendriks et al., 2005, Wight et al., 2002, Wight and Obasi, 2003, Hong et al., 2005, Hargreaves et al., 2004, Linnan and Steckler, 2002a). Due to the relative recency of this form of evaluation, there has been growing consensus and development about what is important to capture in process evaluation, but less of an establishment of tried and tested methods.

Planning and implementing a comprehensive process evaluation can be a complex process, and specifying which stakeholders will be able to offer information on what aspect of the process evaluation may be helpful (Rosato, 2005). In their process evaluation of a trial of daycare for socially disadvantaged families, Oakley et al used a rating scale to assess quality of care, and analysed field notes of process evaluators, questionnaires, and semi structured interviews (Oakley et al., 2004). They also suggest that researchers collect data after the outcome result to enable maximising interpretation of findings. A comprehensive process evaluation looking at all aspects may require a multi-skilled team and adequate time and resources, which may not be available to all research projects. A WHO project appeared only to use quantitative data in their process evaluation and do not clearly report on how some questions were answered (WHO, 1999a). Often full reporting of findings is difficult, and specific issues are discussed in separate publications. The academic pressure to publish multiple articles also often disables comprehensive clarity about studies. For example a process evaluation team reported on the relevance of the intervention to a target group implementation issues and overall findings in separate articles (Buston and Wight, 2002, Buston et al., 2002, Wight et al., 2002).

## ***2.5.7 Difficulties integrating qualitative and quantitative data***

### ***2.5.7.1 Generating and testing hypotheses***

Although Patton holds that the practical mandate of evaluation outweighs concerns about methodological purity based on epistemological and philosophical arguments, there are undoubtedly some difficulties to be overcome when mixing methods and integrating different types of data (Thomas et al., 2004, Patton, 2002a). Process evaluations are often undertaken at the same time as RCTs, and therefore qualitative and quantitative data for the outcome evaluation and the process evaluation are being collected at the same time (concurrently) (Creswell, 2003). The primary purpose of process data is not to methodologically triangulate, but to collect more information that will be useful in explaining outcomes, examining the effect of context, examining implementation, and looking at differential effects in the population (Bottorff, 1997). Some authors, particularly those advocating for RCTs with process evaluation, feel there is benefit in maximising the confidence that qualitative researchers can have in a theory, by opening the theory up to the maximal threat of systematic testing (Bottorff, 1997). However, if theories are generated from process data, to be tested with outcome data, this may indicate a lack of faith in the validity of process data. Some researchers interpret this as prioritising one type of research over another, instead of acknowledging paradigmatic differences. This difficulty is discussed by Riley et al. and Oakley (Riley et al., 2005, Oakley et al., 2004). They suggest listing the factors likely to have analytic power in relation to interpretation of data, and design of strict protocols before the trial, setting out when the data from the process evaluation will be used, and what weight will be given to data. Riley et al. also recommend having regular review meetings with a forum of representatives to help deal with these issues (Riley et al., 2005). Bottorff asserts that only the best qualitative research

should be used in generating hypotheses, and feels that researchers need to be aware that one quantitative study is unlikely to be sufficient to look at all aspects of a theory (Bortorff, 1997). A grounded theory approach to data collection is best suited to this sequence of theory generation and testing. Bortorff also suggests that researchers need to be mindful of 1) the need to evaluate new theories against existing competing theories 2) the need for further qualitative work when aspects of the theory are not well supported, or when new questions are raised by quantitative investigations 3) the fact that the time between qualitative and quantitative data collection and analysis may mean that different factors may influence results.

#### *2.5.7.2 Bias and difficulties of the evaluation becoming the intervention*

There are other concerns with collecting and analysing process data, and integrating it with outcome data. Epistemological purists may argue that it is difficult for an evaluation team to be testing predetermined hypotheses, and yet remain open to whatever emerges from the data. Some research groups deal with this issue by having a separate process evaluation team. Wight and Obasi were also concerned about biasing data collection and analysis if members of the trial team also collect process evaluation data (Wight and Obasi, 2003). Another concern they have is that process evaluation data collection may affect the response of those receiving the intervention, particularly if this makes them reflect and change their behaviour.

#### *2.5.7.3 Ethical dilemmas and informing the development of a trial*

Riley et al. discusses the difficulties of integrating data in a process evaluation of a cluster RCT designed to improve postnatal health of mothers (Riley et al., 2005). The process

evaluation team found that if they acted on qualitative (process) findings, this could jeopardise the integrity of the trial and its ability to answer the question it set out to address. Yet researchers felt it was unethical to continue to do harm to community relationships, local agencies and morale, and limit the ability of the intervention to improve health outcomes of beneficiaries. Not all interventions are flexible enough to integrate process findings, and if outcome measures also change then trials may have to be conducted over a longer period, or with a larger population to maintain statistical power. Riley also found that process evaluation researchers were empowering some views more than others, because the process evaluation team represented that group of respondents, and considered them key informants. Clear protocols should indicate when data from the process evaluation will be utilised, and deal with the ethical concerns before the study begins.

Integral process evaluations may go some way to dealing with many of the weaknesses of RCTs, yet this is an emerging approach that requires negotiation and planning, and there is little established guidance of an optimal process evaluation design.

**Figure 3 Newborn being examined by an FCHV**

Photograph taken by Tom Kelly



### **3 Maternal and Child Health**

The maternal and child health literature is reviewed in order to describe the salience of the intervention, and Nepal specific data is presented. Global movements for neonatal and maternal survival are also described, and current debates and opinion regarding effective interventions is then reviewed.

#### **3.1 Child health**

1960 provides the earliest data on annual numbers of global child deaths, and since then the number has halved – from 20 million to under 10 million in 2006 (UNICEF, 2007b). Some of this decline may be attributed to focussed programmes, such as the WHO Expanded Programme on Immunisation (EPI) and the Control of Diarrhoeal Diseases Programme, and UNICEF'S growth monitoring, oral re-hydration, breastfeeding and immunisation initiative (UNICEF, 1996). There was a steep decline in the under five mortality rate between 1970 and 1994, but this decline did not continue into the 1990s (Ahmad et al., 2000). A series of papers on child survival in the Lancet, acknowledged that gains in child survival have slowed or been reversed (The Bellagio Study Group on Child Survival, 2003). Authors found that half of worldwide deaths in children under five occurred in only six countries, and 90% of deaths occurred in 42 countries. More recent data shows that currently, of the 9.7 million children dying every year, 3.1 million are from South Asia, and 4.8 million are from Sub Saharan Africa (UNICEF, 2007a). The Bellagio group found that cause of death varied by country, and authors noted that most deaths occurred in rural areas. They reported that the most important risk factors for child mortality were: unsafe

drinking water and sanitation; inadequate birth spacing; lack of breastfeeding and non-exclusive breastfeeding. They compared estimates of cause of death with WHO data, (Table 1) and found that death during the neonatal period made up around half of under five mortality.

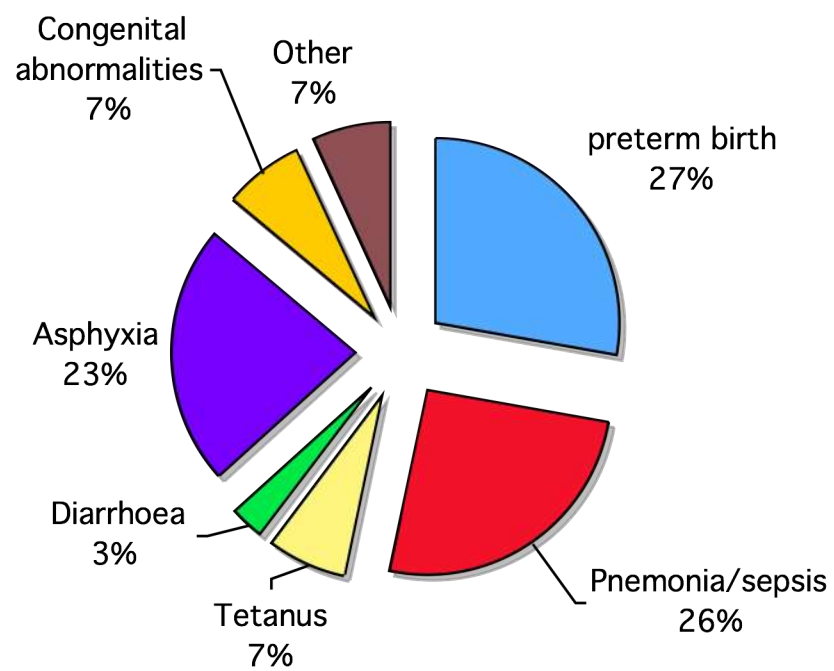
**Table 1** Distribution of death in WHO database and cause of death model

	Proportion of deaths	
	WHO (%)	Model (%)
Neonatal	47.9	52.6
Diarrhoea	17.5	14.1
Respiratory infections	10.4	8.2
AIDS	0.1	0.3
Other	24.1	24.7

(The Bellagio Study Group on Child Survival, 2003)

Black et al. estimated that 10.8 million under-five deaths occurred in 2000, of which 3.9 million of these deaths were neonatal (occurring in the first 28 days of life) (Black et al., 2003). Research shows that the proportion of child deaths attributed to the neonatal period is rising, especially in south Asia: between 1980 and 2000, child mortality after the first month of life fell by a third, but the neonatal mortality rate was only reduced by about a quarter (Lawn et al., 2005). 99% of neonatal deaths occur in low income and middle income countries. Determining the cause of neonatal death is problematic due to poor record keeping, the fact that over half of neonatal deaths occur at home, and the high chance of misclassification. Difficulty assigning cause of death also arises because signs of illness in neonates have a limited repertoire, and may not be illness specific (Osrin, 2006). It is estimated that mortality rates are very high in the first 24 hours after birth, and three-quarters of neonatal deaths happen in the first week of life. Global estimates of cause of death are only possible through statistical modelling, and are presented in figure 4.

**Figure 4 Global causes of neonatal mortality**



(UNICEF, 2007b)



Research has also shown that broader socioeconomic and environmental factors, as well as maternal factors play a pivotal role in neonatal and child survival. An examination of Demographic Health Survey data from 1986 to 1998 in 56 countries, and found that the two most important factors explaining the decreases in child mortality in the 1990s were the decline in malnourished children, and the decline in children living in poor environmental conditions (Rutstein, 2000). Secondary factors were medical care during pregnancy, birth, and during childhood illness with diarrhoea. Socioeconomic factors (electricity and mothers education) were the next most important. Therefore it is not surprising that mortality varies within low income countries, where child mortality rates are several times higher in the poorest 20% of the population than the richest (Gwatkin et al., 2004). As more research is undertaken on the determinants of child mortality, it is evident that there is a need to consider illness specific, and country specific factors that affect mortality (Mulholland et al., 2008).

Research has shown that gender inequalities also affect child mortality. Gender inequalities in education and food allocation, affect child survival – a more educated, well nourished woman is less likely to have a child that will die (Carr, 2004). An analysis of child mortality in India underlined the contribution of maternal characteristics and gender differentials in education, nutrition, and use of health services (Claeson et al., 2000). Girls were more vulnerable than boys, particularly in south Asia (Victora et al., 2003). Claeson states that eliminating gender differences in mortality rates would significantly reduce infant and child mortality overall. Other reports have also found gender inequalities (Das Gupta, 1987, Filmer et al., 1998). For example, in the event of illness, girls were taken to health facilities at more advanced stages of illness, and then to less qualified doctors where

less money was spent on treatment (Filmer et al., 1998). Expenditure on health care in the first two years of life was at least twice as high for sons as for daughters (Das Gupta, 1987).

### ***3.1.1 Neonatal health in Nepal***

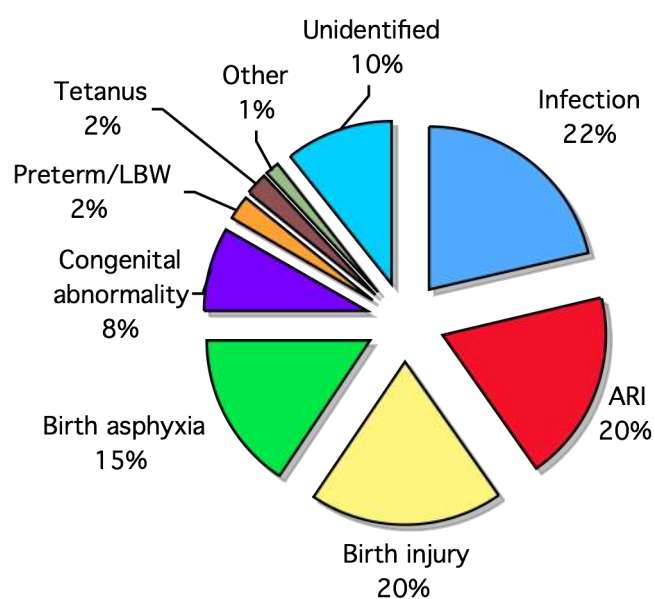
Probably the most reliable data on national neonatal mortality rates in Nepal is from the Demographic Health Survey. Decreasing mortality trends are shown over the past 15 years in table 2, and the current neonatal mortality rate is 33 per 1000 live births, based on a recall of pregnancies in the five years preceding 2006. There have been a number of studies of cause specific mortality in Nepal, and it appears that birth asphyxia is the major cause of death (Morgan et al., 1997, Pradhan and Shah, 1997, Geetha et al., 1995). Data on mortality from urban and rural studies differs and Geetha et al. note the limitations of their study due to the lack of baseline data, the small numbers of babies involved, and the inherent weaknesses of the verbal autopsy approach. Our community based study in rural Makwanpur assessed cause of death through a combination of verbal autopsy and questionnaire data. We found the most common causes of death were: complications of preterm birth, presumptive birth asphyxia and infection (Manandhar et al., 2004). Nonetheless, many newborns die from multiple and interacting causes so a single diagnosis is often arbitrary. The Nepal Demographic Health Survey also collected data on cause of death. A computer algorithm was used to analysed 475 verbal autopsies, 275 of which were neonatal deaths. The algorithm could not assign a cause in 44 out of 475 deaths, and Nepali paediatricians could only agree a cause of death in 9 of these 44 cases. National data concurs with the global data, that infection is a primary cause of death in neonates (Figure 5).

**Table 2** Early childhood mortality rates

Years preceding the survey	Neonatal Mortality rate	Infant mortality rate	Under-five mortality rate
0-4	33	48	61
5-9	43	72	96
10-14	49	82	117

(Nepal Ministry of Health and Population, 2006)

**Figure 5** Neonatal cause of death in Nepal



ARI: Acute respiratory infection  
 LBW: Low Birth Weight  
 (Nepal Ministry of Health and Population, 2006)

### ***3.1.2 Global initiatives for neonatal health***

The World Health Organisation led the successful Expanded Programme on Immunisation in 1974 and the Control of Diarrhoeal Diseases initiative. UNICEF led the GOBI-FFF (Food, supplementation, family planning, female education) initiative, and together these programmes have been called ‘the child survival revolution’ (Schuftan, 1990). In 1989 the United Nations adopted the Convention on the Rights of the Child, which obligates ratifying nations to take appropriate measures to diminish infant and child mortality (Convention on the rights of the child). No human rights convention has ever attained such widespread ratification, nor so quickly (UNICEF, 1996). The campaign for child survival and development reached a peak in 1990 when The World Summit for Children was held. Under the auspices of the UN in New York, this summit held a joint signing of a world declaration and 10 point Plan of Action calling for significant reductions in infant mortality rates and under five mortality rates by the year 2000 (World summit for Children, 1990). In many countries, progress on child mortality over recent years has stalled (Diamond, 2000), and some authors state that this could have been due to a shift of focus away from child survival, caused by HIV/AIDS epidemic, over-reliance on technological fixes (Ruzicka and Hansluwka, 1982, Gwatkin, 1980), programmes of structural adjustment and health sector reform (Reich, 1995).

The Millennium Development Goals (MDGs) may have helped to refocus governments and donor attention on child health again. Signatories committed to “create an environment at the national and global levels alike ... which is conducive to development and to the elimination of poverty.” This declaration led to an agreement on eight goals, the

Millennium Development Goals (UN). Goals four and five relate directly to maternal, neonatal and child survival (Box 3).

**Box 3 Millennium Development goals related to maternal, neonatal, and child survival**

Goal	Health Target	Health indicators
Goal 4 Reduce child mortality	Reduce by two thirds, between 1990 and 2015 the under-five mortality rate	Under-five mortality rate  Infant mortality rate  Proportion of one-year-olds immunised against measles
Goal 5 Improve maternal health	Reduce by three quarters, between 1990 and 2015, the maternal mortality ratio	Maternal mortality ratio  Proportion of births attended by skilled health personnel

Save the Children's Saving Newborn Lives initiative helped to stimulate advocacy for newborn survival, and brought together research groups and programme advocates who emphasised the need to intervene in the neonatal period. An interagency group called The Healthy Newborn Partnership formed in 2000 to promote action to improve newborn health and survival, provide a forum for information exchange, and to enable partnership working (Healthy Newborn Partnership, Access date 27.05.08). Several calls to action resulted from this partnership, and the 2004 Addis Ababa declaration set a target of reducing the global burden of neonatal deaths by 50% between 2000 and 2015, and called for the inclusion of neonatal mortality rate as an indicator of progress towards achieving MDG 4.

In January 2004 the Partnership for Maternal and Newborn Health was formed, and participants stressed the importance of taking a holistic approach to achieving MGDs four and five. The integration of maternal and newborn health was seen as necessary to present a

united and powerful voice at the international level. It aims to do this through developing a single set of consistent messages to ensure that no priority issue is forgotten ([www.safermotherhood.org](http://www.safermotherhood.org), Access date 1.4.09). This is a laudable aim, but not easy to achieve. Several safe motherhood websites view the partnership as an expansion of the Safe Motherhood Initiative (google search on 27.05.08 of ‘partnership for safe motherhood and newborn health’), and other maternal advocates are worried about a loss of focus (Maine, 2007). Perhaps the biggest hurdle to overcome is the lack of agreement on prioritisation of facility based or community based care: the neonatal survival series in the Lancet clearly advocates for such as community based care (among other interventions) that conflict with those outlined in the maternal survival series (Martines et al., 2005).

The Lancet neonatal survival series may also be a key point in the neonatal health campaign (Lawn et al., 2005). The effect of the Lancet series was analysed by authors one year later and they felt that attention and commitment to newborn health had increased in certain areas (Lawn et al., 2006). The newborn mortality rate has not been added as an indicator under MDG 4, but it was included as an indicator to be tracked as part of the ‘Countdown to 2015’ series of meetings planned for the next decade. The Countdown group is a collaboration of individuals and organisations to track the progress towards MDG four and five in 68 countries of highest maternal and child mortality rates in 2005 (Countdown to 2015 Maternal Newborn and Child Survival, 2008). The countdown group appears to progress the collaborative approach between maternal and newborn groups. The first few reports of progress focussed on the individual child or mother, but have since evolved to emphasise the need to focus on ‘the continuum of care of reproductive, maternal and newborn and child health’ (Countdown coverage writing group on behalf of the

countdown to 2015, 2008). The recent statement of a three-pronged strategy necessary to save the lives of women and their newborns indicates a compromise, and is perhaps deliberately vague about facility based or community based care (Box 4) (Countdown to 2015 Maternal Newborn and Child Survival)

**Box 4 Strategy to save women and newborns**

All women must have access to reproductive health care, including contraception, to enable them to control the number and spacing of their children
All pregnant women must have access to skilled care at the time of birth, including timely access to quality emergency obstetric care if needed.
All women and newborns must have access to postnatal care soon after delivery

(Countdown to 2015 Maternal Newborn and Child Survival, 2008)

The countdown group found that there was insufficient data on maternal mortality to track progress to MDG 5, and the countdown group found that only 16 of the 68 priority countries were on track to meet MDG 4. They found that interventions that can be scheduled (antenatal care and immunisation) had greater coverage than clinical-care interventions, which progressed more slowly and had higher levels of inequity.

Contraceptive prevalence, skilled attendance at birth, clinical case management of newborn and child illnesses were areas of less coverage and little progress. Authors concluded that rapid progress is possible but focussed efforts on the areas of least progress are necessary to meet the MDGs.

**3.1.3 Interventions for neonatal survival**

The WHO developed guidelines for optimal care of the newborn in 1996 (WHO, 1996).

Essential Newborn Care (ENC) emphasised cleanliness, thermal protection, initiation of

breathing, breastfeeding, and eye care. Guidelines also covered care of the preterm or low birth weight baby, immunisation and management of newborn illness. Since then, ENC has developed into a comprehensive strategy comprising basic preventive newborn care, early detection of problems or danger signs, and treatment of key problems (Narayanan et al., 2004). Clarity of guidelines has been helpful particularly in training of health workers and clarifying messages for behaviour change communication (BCC) materials but there has been little guidance on how to operationalise or implement ENC.

The second paper in the Lancet neonatal survival series goes some way to guide implementation of interventions for neonatal survival (Darmstadt et al., 2005). Findings were presented from a systematic review of the evidence on the efficacy and effectiveness of interventions with potential to reduce perinatal (seven months gestation to one month after birth) or neonatal mortality. After effective interventions were identified (Box 5), they were then combined into packages based on delivery modes (facility based, outreach, family-community) and their cost effectiveness was calculated. Using models, not empirical data, authors found that antenatal and postnatal care interventions through families and communities could produce a reduction in mortality of 18%-37% (Darmstadt et al., 2005). They argued that this type of intervention could yield early success in advancing neonatal survival especially in settings with weak health systems and high neonatal mortality rates. In a review of Traditional Birth Attendant training, it is also suggested that in places where there is high mortality and weak health systems, a community-based approach could make significant contributions to neonatal survival (Sibley and Sipe, 2006).



To reduce neonatal mortality by over 50% Darmstadt et al. felt that increased coverage of quality health services with good clinical care, plus family and community interventions, was necessary. Although there is a lack of evidence from robust large-scale effectiveness trials in low income countries, authors felt that there is enough evidence to act to save newborn lives, even in countries with ‘suboptimum health systems’ (Darmstadt et al., 2005).

The last paper in the Lancet neonatal survival series reinforces the proposed plan of action (Martines et al., 2005). Community based care, participation and community mobilisation are central themes. Authors found the evidence from community based trials to be encouraging and felt that it is necessary to meet the needs of poorer women who are delivering at home and not accessing health services (Manandhar et al., 2004, Bang et al., 1999, Bhandari et al., 2003a, Morrow et al., 1999, Haider et al., 2000). Community participation to inform the development of policy, disseminate health messages and enable community engagement with issues of neonatal health is proposed as an important component to any delivery mechanism (Martines et al., 2005).

**Box 5** Interventions effective in reducing neonatal mortality or morbidity

<b>Preconception</b> Folic Acid supplementation
<b>Antenatal</b> Tetanus toxoid immunisation Syphilis screening and treatment Pre-eclampsia and eclampsia prevention Intermittent presumptive treatment for malaria Detection and treatment of asymptomatic bacterium
<b>Intrapartum</b> Antibiotics for preterm premature rupture of membranes Corticosteroids for preterm labour Detection and management of breech Labour surveillance for early diagnosis of complications Clean delivery practices
<b>Postnatal</b> Resuscitation of newborn baby Breastfeeding Prevention and management of hypothermia Kangaroo mother care (low birth weight babies in health facilities) Community-based pneumonia case management

(Martines et al., 2005)

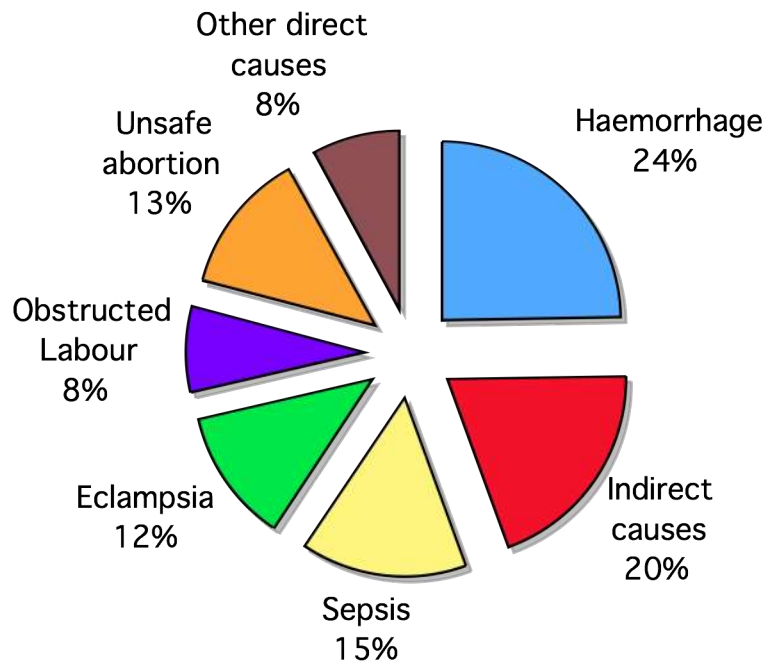
### **3.2 Maternal health**

As with child health, maternal health is usually measured by mortality estimates. Each year, an estimated 529 000 maternal deaths occur, and the global ratio of maternal deaths to livebirths (maternal mortality ratio) is 400 per 100,000 live births (Ronsmans and Graham, 2006). Hill et al estimate that in 2005 there were 535,900 maternal deaths (with a confidence interval of 288,400 – 871,800) (Hill et al., 2007). A maternal death is classified as: the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to, or aggravated by the pregnancy or its management, but not from accidental or incidental causes (WHO, 2007). There is much regional variation in maternal mortality, with Sub-Saharan Africa experiencing a mortality ratio of 100 maternal deaths per 100,000 live births, which is twice as high as the maternal mortality ratio in south Asia. Global inequalities are illustrated by the State of the World's Mothers Report (Save the Children, 2006). It estimates that one in six women in Sierra Leone will die of maternal causes in their life-time, whereas in Sweden, one in 29,800 women will die of maternal causes. Progress in reducing maternal mortality is not uniform across all countries, but globally, the maternal mortality ratio has only decreased at an average of less than 1% annually between 1990 and 2005 (WHO, 2007). Research has shown that Malaysia and Sri Lanka have halved their maternal mortality ratios in seven to ten years (Koblinsky, 2003), but Sub-Saharan Africa experienced only a 0.1% annual decline in this time period, and a non-significant decline of 1.8% from 1990-2005 (Hill et al., 2007). Research has shown that progress towards increased coverage of skilled birth attendance has stagnated or reversed (AbouZahr and Wardlaw, 2001).

Maternal mortality is difficult to measure. Many countries do not have complete and accurate civil registration systems, and women who die at home may not be reported. If a woman's pregnancy status is not known, then a maternal death may also go unreported (WHO, 2007). Even in countries with civil registration systems in place it is likely that maternal mortality is underreported. Data from the US and Europe has shown that the true number of maternal deaths could be almost 200% higher than routine reports (Deneux-Tharaux et al., 2005). There are large margins for error in measurement of maternal mortality. Maternal mortality is often not the primary outcome measure of research due to the expense and difficulty of carrying out large surveys necessary to capture changes in maternal mortality. As a result of these difficulties in measurement, experts have recently advised the use of proxy indicators such as place of delivery, skilled attendance at birth, and perinatal mortality rates to measure progress in maternal survival (Countdown to 2015 Maternal Newborn and Child Survival, 2008).

Research has shown that most maternal death occurs in the immediate postpartum period, and in developing countries it has been found that 45% of maternal death occurs in the first 24 hours after birth, and 80% of postpartum deaths occurred within one week of birth (Li et al., 1996). Global estimates have found that 25% of maternal death is caused by haemorrhage and 20% of deaths are the result of pre-existing conditions exacerbated by pregnancy or its management. Anaemia, malaria, hepatitis, heart disease, and HIV/AIDS are all indirect causes of death (Figure 6).

**Figure 6 Global causes of maternal mortality**



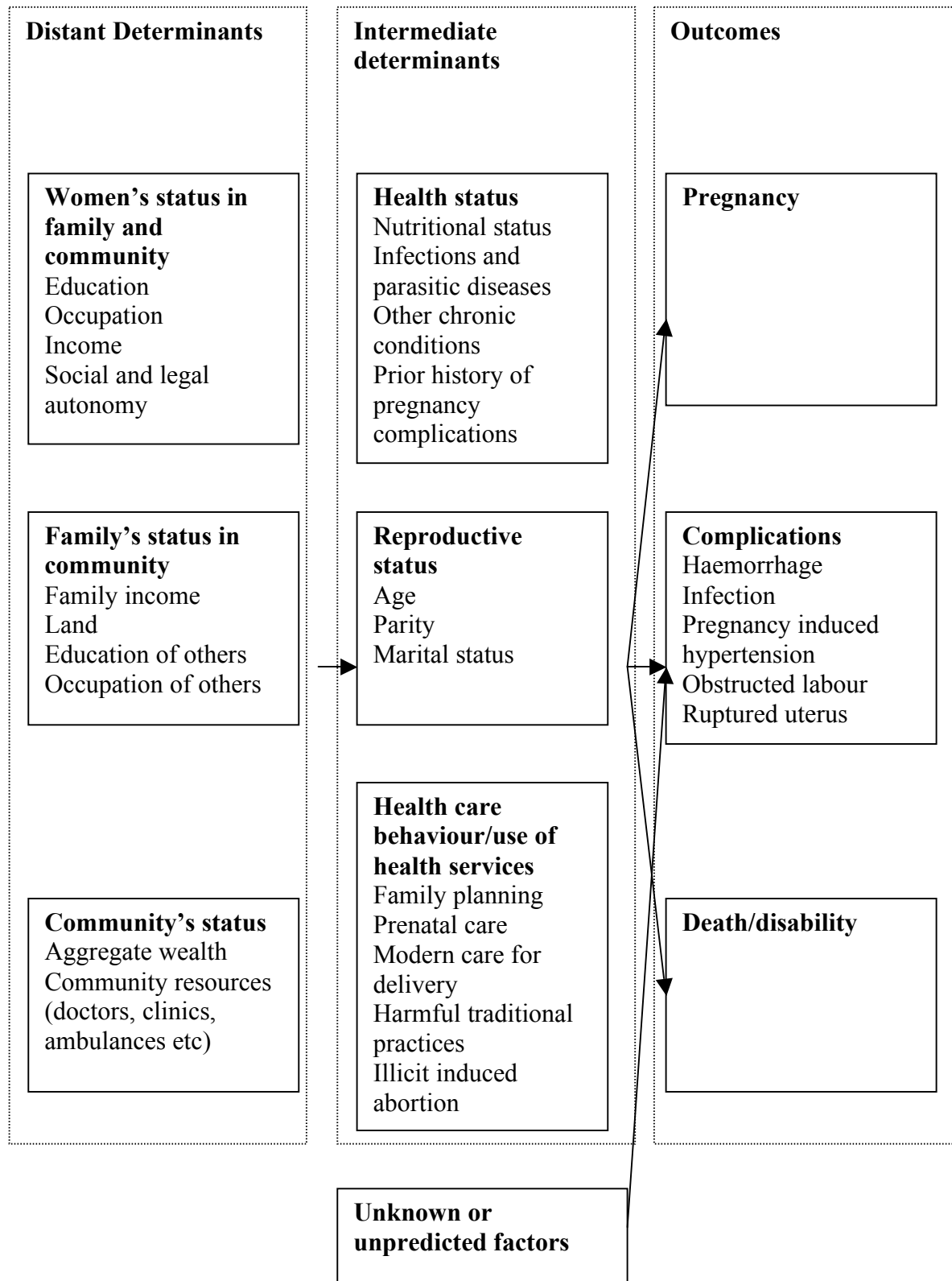
(WHO, 1999b)

Causes of death vary by country and in Latin America and the Caribbean, hypertensive disorders make up 25.7% of death as compared with Sub-Saharan Africa and Asia where hypertensive disorders make up 9.1% of deaths (Khan et al., 2006).

As with child health, there are factors underlying the direct causes of maternal deaths. McCarthy and Maine present a framework for analysing the determinants of maternal mortality, which is based on models from child health, and this includes distant determinants and intermediate determinants (See Figure 7) (McCarthy and Maine, 1992). A statement from WHO, UNFPA, UNICEF, and the World Bank describes underlying causes of death: the low social and economic status of girls and women is a fundamental determinant of maternal mortality in many countries. Low status limits the access of girls and women to education and good nutrition as well as to the economic resources needed to pay for health care or family planning services (WHO, 1999b). Ronsmans and Graham present data from Demographic Health Surveys to illustrate that maternal mortality ratios in the poorest wealth quintile are 4 times as high as in the lowest wealth quintile in countries such as Peru (Ronsmans and Graham, 2006). Houweling et al. also present data from Demographic Health Surveys on inequalities in different aspects of maternity and child care within developing countries (Houweling et al., 2007). They found that in urban and rural areas the poor-rich gap in professional delivery attendance is large, but the rural rich and urban poor have relatively similar levels of professionally attended deliveries across most countries. They found that the differentials in skilled birth attendance between rich and poor families are greater than other types of care (antenatal care, immunisation, ARI treatment, diarrhoea treatment).

A model that has been helpful in explaining care seeking behaviour for maternal ill health is the three delays model (Maine, 1990). Timely care seeking during an obstetric emergency is essential to maternal survival, and this model identifies delays in care seeking and factors affecting access to care. Awareness of danger signs and attitudes to pregnancy can affect a family's ability to recognise illness and act upon this. This is considered to be the first delay: delay in care seeking. The second delay is in reaching the source of care, and this is affected by geography, transportation and funds. The third delay is in receiving appropriate care at a health facility, and is affected by health systems factors.

**Figure 7 Framework for analysing the determinants of maternal mortality**





### ***3.2.1 Maternal health in Nepal***

Nepal has poor maternal health. The State of the World's Mothers report estimates that in Nepal a woman's lifetime risk of dying a maternal death is one in 24 (Save the Children, 2006). Globally, Nepal has one of the lowest rates of skilled birth attendance (Houweling et al., 2007). A study of maternal mortality from 1989 to 1995, estimated a national maternal mortality ratio of 539 (Pradhan et al., 1997). The World Health Organisation estimated a mortality ratio of 830 in 2005 (WHO, 2005), yet the most recent Demographic Health Survey reports a much lower maternal mortality ratio, of 281, based on retrospective data collection of 39 deaths. Sharp falls in maternal mortality have been met with much scepticism, particularly as the past 10 years in Nepal have been characterised by extreme political instability, violent conflict and a reduction of the state's presence in rural areas (Dhakal, 2008). Family Health Division of the Nepal Ministry of Health are conducting further studies to explore the reason for this drop in maternal mortality ratio (Pradhan, 27.08.07). Difficulties of measurement and high margins of error mean that the maternal mortality ratio figure should be interpreted with caution, and efforts to prevent maternal death should remain a priority.

In Nepal, only 19% of births are attended by a skilled birth attendant, and 81% of births take place at home. Nationally, 44% of women received antenatal care from skilled birth attendants, but only 29% received the recommended four visits or more. Figures vary when examining the data by residence or wealth quintile. 85% of urban women, versus 38% of rural women received antenatal care from a skilled birth attendant, and only 5% of women

in the lowest wealth quintile received antenatal care (Nepal Ministry of Health and Population, 2006).

### ***3.2.2 Global initiatives for maternal health***

In her brief history of the safe motherhood movement, AbouZahr believes the focus of international agencies on family planning led to other aspects of women's health, including safety during pregnancy and childbirth, to be neglected (AbouZahr, 2003). The difficulty in measuring the problem of maternal mortality also hampered estimation of the scale of the problem, until 1985 when the WHO announced that half a million maternal deaths were occurring every year. In 1985 Rosenfield and Maine wrote an influential article stressing the need to focus on maternal as well as child health (Rosenfield and Maine, 1985). In 1987, the WHO, UNFPA and the World Bank sponsored the first international Safe Motherhood Conference in Nairobi, which launched the Safe Motherhood Initiative. A broad agenda including improving the status of women was presented, and some feel this weakened the focus on reduction of maternal deaths (Rosenfield, 1997, Starrs, 2006). The campaign for maternal health as a women's right grew, and in the mid 1990s a series of international conferences affirmed this: the International Conference on Population and Development in Cairo in 1994, the Fourth World Conference for Women in Beijing in 1995 and the Social Summit in Copenhagen in 1995. UN agencies and governments, seized upon antenatal care, and training of traditional birth attendants to improve delivery care at the community level, but other important aspects of the closing statement were overlooked (Starrs, 2006). In 1997 there was a conference in Sri Lanka where disappointment was expressed that not more had been done for maternal health. The failures of previous approaches were acknowledged and health sector interventions designed to increase

women's access to professional medical care were emphasised (AbouZahr, 2003). The initiative has pinned down key messages to ensure that focus on reducing maternal death is maintained (Box 6), and there is now much greater clarity and consensus about effective strategies for reducing maternal mortality.

**Box 6 Key messages on safe motherhood in 1997**

*“Every pregnancy faces risks”* emphasised that any pregnant women can develop life-threatening complications with little or no advance warning, so all women need access to quality maternal health services that can detect and manage life-threatening complications.

*“Ensure skilled attendance at delivery,”* acknowledged the importance of having a health-worker with midwifery skills present during childbirth, backed up by transport in case of emergency referral as required. Traditional birth attendants, trained or untrained were excluded from the definition of skilled attendants, because they lacked the clinical skills, drugs and equipment, or infrastructure to manage complications such as haemorrhage, eclampsia, or severe infection.

*“Improve access to quality maternal health services”* emphasised the importance of both economic and interpersonal aspects of care including the capacity to provide emergency obstetric care.

(Starrs, 2006)

There was growing involvement of the medical profession in the maternal survival movement, and an increase in partnerships to address maternal health (Maine, Accessed 23.5.08). The white ribbon alliance, and many other initiatives have been launched (for example WHO's Making Pregnancy Safer Initiative, UNICEF's Women Friendly Health Services Strategy, the World Bank's Safe Motherhood Action Plan, and JHPIEGO's Maternal and Neonatal Health Programme). In December 2000 maternal mortality was included in the health and development priorities of the Millennium Declaration, which explicitly sets targets to reduce maternal mortality by 2015. In 2005 the Safer Motherhood Initiative merged into the Partnership on Maternal, Neonatal and Child Mortality, which presented an opportunity to work along a continuum of care, from the community to the hospital (Maine, Accessed 23.5.08). Recently, the Women Deliver Conference in October 2007 hoped to save the lives of women, mothers and newborns by mobilising increased investment and commitment on the part of governments, NGOs and donors (Closing statement: Women deliver conference, 2007). The closing statement emphasised partnership working, increased access to comprehensive care for women, and the need for resources and political commitment (Box 7).

**Box 7** Closing statement (describing what is necessary to improve maternal survival) from the Women Deliver conference October 2007

Recognise, build and strengthen synergies between health and other sectors
Gain the commitment of government and donors to prioritise and support the pillars of comprehensive reproductive health services, skilled care during and immediately after pregnancy and birth, and emergency care when life-threatening complications develop.
Resources to be mobilised, allocated and used effectively, political will, and accountability led by and driven by civil society.

(Closing statement: Women deliver conference, 2007)

### **3.2.3 Interventions for maternal health**

The diversity of country contexts and the multifaceted nature of maternal health and its determinants could make improving maternal health a complex task, but many argue that there is a need to work with existing evidence, and take a few key strategic choices to ‘get on with what works’ (Campbell et al., 2006). Some suggest that there is scope to prevent and manage maternal illness at the community level (Costello et al., 2004). In contrast, the Averting Maternal Death and Disability Programme advocated for a focus on treatment of maternal health problems, as it concluded that only one direct cause of maternal mortality could be prevented (unsafe abortion) (Maine, 1997). Campbell et al also reviewed the evidence and concluded that a health centre intrapartum-care strategy is likely to be the most likely way to bring down high rates of maternal mortality (Campbell et al., 2006). This strategy would be a comprehensive package with planned distribution channels to achieve high coverage, with endorsement from governments and populations. Antenatal care, postpartum care, family planning and safe abortion are further opportunities to address maternal mortality (Campbell et al., 2006). Traditional Birth Attendant (TBA), and community based health worker strategies were not held to be feasible. They are an

unattractive strategy because of the difficulties of supervision, ensuring adequate referral and transport links, and the evidence suggesting that their outreach service delivery is minimal. Campbell et al. cite a systematic review of TBAs (Sibley et al., 2004) and research in Pakistan (Jhokio et al., 2005) to substantiate their arguments against the use of TBAs. The review included 16 publications, but only three of the studies included in the review analysed the effect of TBA training on detection and referral of obstetric complications. The review cites small positive significant associations between TBA referral behaviour and maternal service use, but that inadequacies in the studies make this difficult to attribute to training of traditional birth attendants. The Pakistan study reports non-significant differences in maternal mortality, as their study was inadequately powered to detect difference in maternal mortality. This suggests that TBA strategy to reduce maternal mortality has not been evaluated thoroughly.

A strategy to reduce maternal death needs to encompass the continuum of care from community to facility - skilled birth attendants without comprehensive facilities and adequate referral would be ineffective, as is strengthening health services without enabling access and adequate referral. This type of comprehensive intervention requires long-term funding and commitment from national health systems (Filippi et al., 2006, AbouZahr, 2003).

### **3.3 Research gaps for maternal and newborn survival**

The literature is unanimous in its calls for more research and effective monitoring of interventions to improve maternal and neonatal survival (Lawn et al., 2005, Campbell et al., 2006). Advocates believe there is enough evidence to act to save mothers and newborns,

yet more research is necessary to inform the development of interventions, and develop effective implementation strategies. Both maternal and neonatal survival literature calls for improved monitoring to:

- Measure the effectiveness of programmes
- Find out the most effective delivery mechanisms for programmes
- Find out how to ensure equitable access to care
- Evaluate cost effectiveness.

In addition, maternal health advocates feel it is important to find out how to finance maternal health services, and the neonatal advocates prioritise research about the effectiveness of disease specific prevention and treatment interventions, improving understanding of how to mobilise communities and create demand for services, and how to translate policy into action (Bhutta et al., 2005, Martines et al., 2005, Filippi et al., 2006). In-country factors can affect the effectiveness of interventions, and therefore research in diverse settings is necessary, with adequate description of the political, geographical and socio-cultural context in which the research was carried out.

**Figure 8 Newborn and grandmother in Nepal**

Photograph by Tom Kelly





## 4 An introduction to Nepal

### 4.1 Population

Nepal is a small country sandwiched between Tibet and India with a population of 27 million (The World Bank, 2008). Nepal has three distinct ecological zones: mountain, hill, and plains. Only 7% of the population live in the harsh mountain terrain despite this making up 35% of the total land area of Nepal. 44% of the population live in the hill area where the urban capital of Kathmandu is situated. The fertile plains are home to 48% of the population and transportation and communication facilities are more developed in this area. 86% of the population live in rural areas (Central Bureau of Statistics, 2001). Life expectancy has been steadily increasing and is currently 63 (The World Bank, 2008). The total fertility rate has decreased from 4.1 births per woman in 2001 to 3.1 births per woman in 2006, and contraceptive use has increased by 70% over the past 10 years to 44% (Nepal Ministry of Health and Population, 2006). Nepali women tend to marry young, although slight increases in age at marriage have been recorded (Table 3).

**Table 3** Age at marriage in Nepal

	1996	2001	2006
Age at marriage	16.2	16.6	17.2

(Nepal Ministry of Health and Population, 2006)

## **4.2 Politics and administration**

There are 75 administrative districts in Nepal, each divided into Village Development Committees (VDC) (3915 in total) and municipalities (58 in total) (Nepal Ministry of Health and Population, 2006). Each VDC is divided into nine wards. At district level, administration has been conducted through a District Development Committee that includes VDC representatives (National Planning Commission, Accessed 1.04.09).

An oligarchy of Rana Prime Ministers governed feudal states until 1951 when this was replaced by a monarchy. After the 1990/91 revolution, Nepal became a constitutional monarchy. A decade long Maoist insurgency has shaped Nepal's recent political history, and claimed over 13,000 lives. The insurgency grew out of disillusionment with the political system and anger at persistent caste discrimination and poverty. The movement became well organised and well armed, and used tactics of forced education and intimidation to gain power, especially in remote areas. During this decade-long conflict, many human rights abuses were committed by government forces and Maoists, including extortion, kidnapping, and execution. Human rights groups reported that 3000 people disappeared during the conflict. Of these, 937 are still missing (International Committee of the Red Cross, 2007). Movement of goods and people was severely restricted, and national and district level strikes often paralysed the country. Research found that women's access to essential obstetric care was restricted because of difficulties of transporting women, particularly at night. Access was also impeded by fear, increased poverty, and, in some cases, health personnel had fled rural postings due to harassment by Maoists (Beun and Neupane, 2003).

The King seized power for a year before the people's uprising in 2006, which ultimately led to the recent constituent assembly elections. The Maoists received the majority vote and the Assembly voted to declare Nepal a Republic in April 2008. There are hopes for political stability to enable economic development.

### **4.3 Economy**

Most of the population depends on agriculture for their livelihood, which accounts for 34% of Nepal's Gross Domestic Product (The World Bank, 2008). Many families in Nepal depend upon relatives working abroad, and the number of families receiving remittance rose from 23% to 32% between 1996 and 2004 (Bennett et al., 2006). Nepal's Gross National Income per capita in 2006 was 320 USD (The World Bank, 2008). The Nepal Living Standards Survey found that the number of people living below the poverty line had dropped from 42% in 1995/6 to 31% in 2003/4, but economic growth is slow (cited in (Bennett et al., 2006). Nepal's Human Development Index is ranked 142<sup>nd</sup> out of 177 countries (Bennett et al., 2006). Half of Nepali households do not have a toilet facility, and it takes half an hour or longer for one in ten households in rural areas to access their drinking water. 57% of households in rural areas do not have access to electricity (Nepal Ministry of Health and Population, 2006). Only 30% of the population have easy access to all weather roads (The World Bank, 2008).

### **4.4 Status of women in Nepal**

The 1990 Constitution described Nepal as a multi ethnic, multi-lingual and democratic kingdom and declared that citizens are equal irrespective of religion, race gender caste tribe

or ideology. Yet women remain treated as subordinate citizens. The law denies women equal inheritance rights and the right to pass citizenship to their children. Existing laws are inadequate to deal with sexual offences and there is no law to deal with sexual harassment (Bennett et al., 2006). Women's literacy rates lag behind that of men, although school enrolment rates are increasing (Nepal Ministry of Health and Population, 2006). Women face much greater economic insecurity than men, as their access to what has traditionally been the primary means of production has always been indirect and dependent on their relationship as daughter, wife, or mother of a land owning male. In a recent survey, only 7% of households reported female ownership of livestock despite the fact that this is a predominantly female task, and many organisations have targeted women with these types of programmes (Bennett et al., 2006).

#### **4.5 Ethnicity**

Interlinking political and economic activity with the Hindu caste system consolidated political and economic power. Priestly Brahmins were at the top of the ritual order (see Figure 9), merchants and peasants and labourers were next, and beneath everyone was the occupational groups, considered 'untouchable'. The indigenous groups (janajatis, generally of Mongoloid descent) occupied middle status, although are not part of the Hindu caste system. Although caste based discrimination was abolished in 1963, recent research suggests that caste is a powerful predictor of social inclusion and empowerment (Bennett et al., 2006).

The 2001 census listed 103 ethnic or caste groups in Nepal (Central Bureau of Statistics, 2001). About 80% were of Indo Aryan origin, and 17% are of Mongoloid origin. Groups

of largest population were two high caste groups: Chhetri 16%, Brahmins 13%. Others that made up more than 5% of population were janajati indigenous groups: Magar 7%, Tharu 7%, and Tamang 6%. The official language is Nepali and is the mother tongue of about half of the population. 91 other languages were identified, of which Maithili and Bhojpuri were spoken by 12% and 8% of the population respectively. Over 80% of Nepalese are Hindu, and 11% of the population is Buddhist (Central Bureau of Statistics, 2001).

**Figure 9 The Nepal caste system**

Braham Chhetri High Caste Newar Tagadhari “twice born”	High caste
<i>Matwali</i> “liquor drinking” Unenslavable Enslavable	Non-caste Janajati/Indigenous peoples
<i>Pani Na Chalne</i> “water-unacceptable” Muslims and foreigners	Low Caste
<i>Acchut</i> “untouchable”	Dalit

\*shaded area indicates Hindu caste groups

(Bennett et al., 2006)

#### **4.6 Nepal's health system**

Nepal introduced primary health care from the early 1980s (Nepal Ministry of Health and Population, 2006). There are tertiary hospitals in the centre, zonal and district hospitals at nodal points in the periphery, and a hierarchy of primary health centres, health posts and sub-health posts at district level. Each level serves as a referral point for the one below. The Sub-Health Post functions as the first institutional contact point, but in practice, it is a referral point for traditional birth attendants (TBAs) and female community health volunteers (FCHVs), and a venue for community-based activities. The Sub-Health Post is a nodal point for preventive, curative and referral services. There is roughly one health facility per Village Development Committee.

There is approximately one female community health volunteer (FCHV) per 7000 population, which is roughly nine per VDC. On recruitment, the FCHV should be married and literate, and is given 24 days of training from the District Public Health Office (Nepal Ministry of Health, 2003). They are unpaid workers but are given some funds to buy medicines and contraceptives as a small business platform (Government of Nepal, 2065). They are under line supervision by Village Health Workers. They are expected to conduct health promotion, support immunisation outreach, provide some first aid, and distribute oral rehydration salts, iron supplements, vitamin A, and contraception. They also should convene monthly women's groups (Nepal Ministry of Health, 2003). In addition, FCHVs are asked to participate in many community based programmes, and their activities are often supported by NGOs. One NGO, the Nepal Family Health Programme has wide

national coverage, and supports FCHVs to diagnose and treat childhood pneumonia (Child Health Division, 1997).

When the TBA training programmes were brought in, there was also usually one TBA per ward. Although TBAs are still part of the strategy to reduce neonatal and maternal mortality support for TBAs has waned and their coverage is not uniform (Nepal Ministry of Health and Population, 2008). Other health care providers at the community level are ayurvedic practitioners and traditional healers.

#### **4.7 Recent national approaches to maternal and newborn health**

Targets have been set to improve newborn and maternal health in the national five year plan (HMGN, 2003), and strategies have been implemented to enable progress towards meeting MDGs four and five (Nepal Ministry of Health and Population, 2006). Nepal has a national Neonatal Health Policy, and donor organisations are currently working with Child Health Division, Ministry of Health to implement a community based newborn care package. The National Safe Motherhood Programme is supported by UK Department for International Development, and works with several NGOs to improve maternal and neonatal survival (Support for Safe Motherhood Programme, 2007). The Programme focuses particularly on the poor and socially excluded, and is comprised of a community based equity and access programme, a maternity incentive scheme, the implementation of a skilled birth attendance policy, and provision of safe abortion services. It also aims to improve maternal and neonatal health services through training and infrastructure development.

#### **4.8 Intervening to improve maternal and newborn health**

There are many factors affecting newborn and maternal survival in Nepal. This section briefly describes some factors that are specific to Nepal, and were considered in the design of the intervention that this thesis evaluates. Some issues are common across South Asia, and therefore literature from South Asia is also discussed. Factors affecting maternal and neonatal survival are presented here in a linear manner although it is acknowledged that these factors are complex, often interdependent, and usually household decisions are made on the basis of a combination of factors (Mackian et al., 2004).

The demographic characteristics of the population of Nepal go some way in explaining its high maternal and neonatal mortality. As discussed previously, factors such as poverty, early marriage, early pregnancy, lack of education, malnourishment of pregnant women, increased susceptibility to illness due to environmental factors etc., can all lead to illness or death (Mosley and Chen, 1984, McCarthy and Maine, 1992). In addition to these factors, most women give birth at home without a skilled birth attendant (Nepal Ministry of Health and Population, 2006), and delay seeking health care, or encounter delays in receiving health care (Erickson, 1995). Preference for home delivery exists for many reasons: cost, accessibility, quality of care, lack of community participation, concepts of illness and healing, and cultural norms.

##### *4.8.1.1 Cost*

Institutional deliveries are expensive in terms of time, travel, subsistence and cost of services (Borghi et al., 2006, Nahar and Costello, 1998). Poor families do not have access



to the resources needed for an institutional delivery and expenditure on health can have a catastrophic effect on families (McIntyre et al., 2006, Narayan and Petesch, 2000).

#### *4.8.1.2 Accessibility and quality of care*

Lack of infrastructure and the topography of the country mean that there is limited access to health services in rural areas, particularly in hill and mountain districts (Furber, 2002).

There is evidence to suggest that the removal of physical barriers to access can only be expected to lead to a limited increase in uptake (Jahn et al., 2000, Acharya and Cleland, 2000, Hotchkiss, 2001). Quality of care is generally low (Pathak et al., 2000, Maternal Health Study (MNPI), 2002), and institutional problems include: absenteeism, lack of staff support, insufficient or intermittent supply of medicines and equipment, and deficiencies in the referral system (Carlough and McCall, 2005, Chhetry et al., 2005, Justice, 1983, Rath et al., 2007). A recent study also found that women were fearful of maltreatment from health workers (Powell-Jackson et al., 2008).

#### *4.8.1.3 Community participation*

Poor service quality may be at least partly the result of users having little voice in the design and management of services (Bruce, 1990). In Nepal, community participation in planning and managing local health services is low. Local committees of health institutions in Nepal may have little accountability to their communities and the level of representation of beneficiaries (particularly women and low caste groups) is low (Manandhar, 1996, Sepheri and Pettigrew, 1996). Research has suggested that increased inclusion of low caste community members on political bodies may promote the financing and sustainability of

primary health care (Bashai et al., 2002). The dissolution of local democratic structures (due to the insurgency) has prevented committees from functioning properly.

#### *4.8.1.4 Concepts of illness and healing and cultural norms*

In Nepal, perceptions about causes of illness and cultural beliefs affect care-seeking behaviour. There are some commonalities of beliefs and practices within Nepal and across Asia, which are discussed here, but an extensive discussion of the literature on neonatal and maternal care-seeking and cultural beliefs is beyond the scope of this thesis. This review focuses on cultural practices and beliefs that may cause harm, and it is acknowledged that many cultural practices may have a positive effect on maternal and neonatal survival.

Illness is shaped by culture and refers to an individual's own perception and reaction to deviations of what is perceived as a healthy condition. Illness is connected with meaning and values, and is constructed within a context (Kleinman, 1980). Therefore, definitions of cause of illness often differ from allopathic definitions of a malfunction in the body. In Nepal, anthropologists have documented the complex links between place, personal circumstance, religion, ayurveda and illness (Pigg, 1989, Kristvik, 1999). It is often believed that illness manifested on the physical level is due to an imbalance in psychological or spiritual aspects of the individual. Ayurveda is a holistic medical tradition influenced by science and both the Hindu and Buddhist religions. It stresses the maintenance of good health by maintaining balance between 3 *doshas* (substances) that humans possess (Pole, 2006). This balance can be maintained through diet, exercise, and meditation. A healer is sometimes necessary to correct an imbalance, or perform demonic exorcism when a body is interfered with by a spirit which causes illness (Wirth, 1995, Pigg, 1995, Hoff, 1992).

Illness may be caused by ghosts, evil spirits, by others putting curses, or by coming into contact with someone who has suffered at the hands of a spirit or ghost (Tamang et al., 2001). Spirits are often perceived to be place specific, therefore particular places are avoided at times of risk. Often, illnesses caused by spirits can only be cured by a person with local knowledge, and the ability to mediate between the spirit world and the 'human' world (Stone, 1976, Pigg, 1989). The old, the young, and pregnant women are perceived to be particularly vulnerable to these forces, as are those who do not follow social norms. Ghosts of women who have died in childbirth, or still born children, or ghosts of childless women are thought to taunt women and newborn babies (Blanchet, 1984, Manandhar, 2000b).

Maternal and neonatal care seeking behaviours are affected by these beliefs in several ways. The home and community is perceived as a safer place - the 'risky' places and local spirits are known, and systems to appease them are known by local healers. Local healers possess knowledge about local circumstances, local interpersonal relations, and local spirits, and they are believed to be able to communicate with spirits (Desjarlais, 1992, Jackson and Jackson-Carroll, 1987). Therefore healers are an essential part of the curing process, and care is routinely sought from them during illness, particularly in rural areas (Osrin et al., 2002, Jimba et al., 2003). Nowadays there is increasing syncretism or pluralism in belief systems and in care seeking behaviour, and systems are not mutually exclusive (Pigg, 1995, Reissland and Burghart, 1989a). Self-medication is also common, and the use of medicine shops, and private practitioners is widespread where they are accessible and affordable (Kafle et al., 1996, Dhungel, 1992). This preference for care in

the home or community can delay care seeking in the event of maternal or neonatal illness which is often highly risky (Mesko et al., 2003, Sreeramareddy et al., 2006a).

In the Nepali context, the Hindu religion also affects concepts of illness, healing and death, particularly the concept of *karma*, that every action has a reaction. Reincarnation is dependent on abiding by rules of social engagement and maintaining ritual purity, and the situation you are born into is predetermined by actions of the previous generation (Bennett, 1983). Abiding by social rules of engagement, and maintaining social structures has also been cited as a reason for behaviours (or lack of action) during the perinatal period (Manandhar, 2000a, Mesko et al., 2003). Pregnant and postpartum women do not wish to bring shame on the household, or affect the fate of future generations. Other authors feel that, over and above religion, routine health behaviours express social structures, and can sustain social cohesion in times of stress and anxiety, and this can also explain reasons for some behaviours (Jackson and Jackson-Carroll, 1987, Manandhar, 2000a).

The concept of fatalism affects perceptions about the extent of control that can be exercised in curing illness, and may mean people are less motivated to practice allopathic preventative care behaviours. The perception that the fate of an individual is determined by a divine or powerful external agency, and the actions of previous generations, is expressed locally by exclamations of '*ke garne?*' - what to do? – and affects many aspects of life in Nepal (Bista, 1991). The National Safe Motherhood Project found that fatalism affected the working culture of health workers and implemented 'Appreciative Enquiry' training to motivate health workers and improve service delivery (Abbatt, 1999). Winch et al believe that there is an overemphasis on fatalism in explaining care-seeking behaviour, as they

found that many actions are taken by families to prevent and treat illness in the neonate (Winch et al., 2005). They argue that although some of these actions may not match with those prescribed by allopathic medicine, the recognition of illness and motivation to take action can be built upon in the design of interventions to improve newborn health.

Many practices and behaviours relevant to perinatal health are linked to ayurvedic and religious beliefs, but vary by place and ethnic group (Manandhar, 2000a). One practice that is relatively common in Asia is the period of post partum confinement of mother and baby. Winch et al. review the literature around this practice, and conclude that confinement is usually related to rites of passage, and marks the transition from one stage of life to another (Winch et al., 2005). When a baby is born, both mother and baby are believed to be in a liminal state, between worlds, and particularly vulnerable (Molnar, 1984). Seclusion for a certain period of time (around two weeks in Makwanpur, Nepal) helps keep the mother and newborn safe from spirits, and contains the ritual pollution caused by childbirth (see below). During this time it is also important that bodily equilibrium is regained. During pregnancy, the body is perceived to be in a gradually heating state (Messer, 1989). Morning sickness is caused by this 'heat', and overheating of the body is understood to cause miscarriage (Nichter and Nichter, 1996). Perceptions that the postpartum woman and baby are in a 'cold' state after childbirth has been documented throughout Asia (Winch et al., 2005). To regain 'balance', actions are taken to heat the mother and baby (Laderman, 1987, Nichter and Nichter, 1996). In Nepal, it is common to feed the mother 'heating' foods, and they are wrapped up warmly, and are massaged by female family members with heating, 'pure', mustard oil - often in the direct sunlight (Reissland and Burghart, 1989b, Reissland and Burghart, 1988, Bennett, 1983). Seclusion is broken by a ceremony. In

Nepal, this is a baby naming ceremony (*nwaran*) (Tamang et al., 2001, Molnar, 1984). The perceptions of vulnerability of the newborn during the first week of life and the perceptions about the liminal state of mother and newborn can affect preparations for childbirth. Families often don't prepare materials for birth, or buy anything for the baby because this will expose the mother and baby to risk by 'tempting fate' and angering gods and spirits (Beun, 2002, Tamang et al., 2001).

Another reason for seclusion during the postpartum period is the belief that childbirth is polluting, and this pollution should be contained (Levitt, 1993). This has been documented in some countries in Asia and originates from Hinduism (Sarmin et al., 2003, Goodburn and Rukhsana, 1995). Menstruation and the bodily fluids of childbirth are considered 'dirty' and impure, and contact with these should be prevented (Bennett, 1978, Gray, 1995). Male family members, particularly, are not allowed to touch or see a post partum woman, and she is not allowed to cook or wash, and her food is restricted (Bennett, 1983, Tamang et al., 2001, Nichter and Nichter, 1996). The seclusion of mother and newborn can prevent care-seeking during illness or for routine postnatal care (Ahmed et al., 2001, Jackson and Jackson-Carroll, 1987, Matsuyama and Moji, 2008, Thapa et al., 2000, Thapa, 1996).

Food restrictions during pregnancy and the postpartum period are common in Asia and often are in accordance with ayurvedic classifications of hot and cold food, and the gradually heating state of the body during pregnancy, and the cold state of the body postpartum (Messer, 1989). For example, in Makwanpur women were commonly given 'heating', 'strong' chicken soup to enable them to regain their strength after childbirth (Tamang et al., 2001). In Dhanusha postpartum women are given 'heating' raw sugar and

ginger (Ormston, 2009). Some food restrictions are not in accordance with Ayurvedic principles, for example during pregnancy women should not eat green leafy vegetables (*saag*) because their baby will have long ‘stringy’ hair (Chaudhary, 2008). Other food restrictions appear more for practical reasons, for example in Dhanusha water and food is restricted postpartum, so that a mother does not have to urinate or defecate frequently while she is in postpartum seclusion (Ormston, 2009). In some areas of Nepal, fasting is common during pregnancy in order to please the gods and have a boy child (Ormston, 2009). Food intake is sometimes restricted, in order to limit the size of the baby and enable an easy birth - ‘eating down’ during pregnancy has been documented in order to have a small baby (Manandhar, 1999, SEWA, 1994). This practice is not common in Makwanpur and women tend to work hard, or tie a cloth around their waist to limit the size of the baby, and food intake is restricted by socioeconomic status (Tamang et al., 2001). Some literature suggests that Tamang women do less ‘heavy’ work during the last trimester of pregnancy if their socioeconomic status allows (Panter-Brick, 1989). Tamang is the most populace ethnic group in Makwanpur. Research by Nichter and Nichter in South India has detailed the perceptions of women about how the foetus is sustained while inside the womb, and often women believe that the baby receives the same food that they consume (Nichter and Nichter, 1996, Over, 2002). This affects what women feel is appropriate to eat during pregnancy. Nichter and Nichter also found that women may ‘eat down’ in order to maintain sufficient space in their bodies for the baby, and prevent the space being filled with food or gas, and harming the baby. This is also a common perception in an area of Nepal that borders India (Over, 2002). Some food restrictions are likely to have survival implications for the mother and neonate, particularly in populations of women who are poor

and do not have a balanced diet even when they are not pregnant or postpartum (Christian et al., 1998).

Other cultural practices may harm the neonate. For example, infection of the umbilical cord may be caused by the application of cow dung on the stump (World Health Organisation, 1998). Cow dung is applied as it is considered 'pure' in the Hindu religion (Bennett, 1983). Massage of the neonate with mustard oil may reduce the capacity of the skin to act as a protective barrier (Darmstadt et al., 2002). The use of prelacteal feeds may also expose the neonate to infection (Bhutta et al., 2005). Honey, oil or ghee may be given to the neonate to ensure the future 'sweetness' of life, and diuretics are sometimes given to the baby in order to clear the mucus consumed during child birth (Tamang et al., 2001, Goodburn and Rukhsana, 1995). Colostrums are sometimes not fed to neonates due to the perception that it is 'dirty' or 'stale' milk (Prasad, 1994, Manandhar, 1999).

#### *4.8.1.5 Status of women*

The subordinate status of women in the family can limit their access to education and information, which may mean they are less aware of good care behaviours (Furuta and Salway, 2006, Sreeramareddy et al., 2006b, Joshi, 1994). 'Lack of knowledge' is sometimes stated as a reason for not seeking care, or not practicing preventative behaviours (Dhakal et al., 2007, Beun, 2002). This may be an oversimplification of understandings of health and illness and the rationality of health care behaviours. Food allocation is also affected by women's status in the family (Gittelsohn and Thapa, 1997, Gittelsohn, 1991, Chen et al., 1981). Social norms make some women embarrassed about their pregnancy, which may prevent them from talking about health problems or seeking care (Mesko et al.,



2003, Tamang et al., 2001). Low status in the family means that often, women do not have access to the resources necessary to seek health care (Morrison et al., 2008b, Ahmed et al., 2000, Okojie, 1994) and they are unable to seek care without consultation with other family members (Furuta and Salway, 2006, Powell-Jackson et al., 2008).

## **5 Participation and health**

This chapter describes the theoretical underpinning for the intervention that this thesis evaluates. The intervention was designed on the basis of evidence suggesting the effectiveness of taking a participatory approach to maternal and newborn health. A brief description of participatory approaches to health in low-income countries is given. Thereafter, the literature is reviewed to describe the advantages of this approach, and the difficulties. The literature on community participation for newborn and maternal health in low-income countries is reviewed and the participatory intervention that this thesis examines is described in detail.

### **5.1 Participation and primary health care**

The language of participation has been in the economic development literature since the 1940s, (Hickey and Mohan, 2004, Rifkin, 1990). The movement for community participation in health care may have resulted from state failure and failure of top-down approaches, and post-colonial guilt (Cueto, 2004). Decolonisation exposed the weaknesses of the curative, hospital approach to healthcare, and inequities in this approach were revealed (Rifkin and Walt, 1986). This led to a shift to preventive, decentralised, community care based on epidemiological priorities (Rifkin, 1990). Health was tied to the economic and social development of countries, health defined as the absence of illness, was replaced by a broader definition of health as social and economic well-being (Robinson, 1980). This led to the concept of primary health care. The declaration of Alma Ata formalised the importance of community participation in primary health care stating that

people have the right and duty to participate individually and collectively in the planning and implementation of their health care (WHO, 1978).

In the following years, both primary health care and participation fell out of favour as many became disillusioned by participatory approaches that did little to challenge existing power structures, and primary health care fell short of expectations (Rifkin, 1996). Some felt that holistic Primary Health Care was largely undeveloped due to its utopian ideas without financial commitment or clear methodology (Lawn et al., 2008, Cornwall, 2000). Policy makers and implementers were unsure how local voice could be integrated into the ongoing development and strengthening of national health systems (Skeet, 1984, Gish, 1979). Primary health care was rapidly replaced by selective primary health care (Cueto, 2004, Unger and Killingsworth, 1986, Walsh and Warren, 1979).

The idea of primary health care has attracted renewed interest, as progress towards the MDGs is uneven, and attention is re-focussed on health inequalities, poor coverage of basic health care and lack of engagement by communities in health systems (Haines et al., 2007). Haines cites a growing body of evidence that supports the revitalisation of primary health care as an effective strategy. In a recent statement, the director general of the WHO stated that she wanted to revitalise the vision laid out by Alma Ata, and she felt that both vertical and horizontal programmes are needed to meet health challenges (Horton, 2008).

Participation rhetoric remains popular and appears well integrated into mainstream health and development discourses. Participatory research may be gaining in popularity (Baum et al., 2006) and research ethics committees often advise the involvement of stakeholders in

the design and execution of research (Caballero, 2002). Critiques of participation have perhaps led to a more informed, less idealistic approach, where practitioners can be aware of the pitfalls and difficulties of participation and strive to overcome them (Hickey and Mohan, 2004, Pratt, 2000). Another trend appears to be a separation of participation and empowerment - participation is now considered as a route to empowerment, with programmes stating goals of empowerment as opposed to participation (Bennett and Gajurel, 2006, Laverack, 2007, Eyre and Gault, 2003, Kar et al., 1999).

## **5.2 The advantages of participatory approaches**

The declaration of Alma Ata indicates what a participatory approach to health hoped to achieve: the organisation and delivery of health services would be more cost effective, as there would be greater access to fundraising opportunities and availability of volunteers (WHO, 1978). Resources would be directed towards felt needs, and therefore service delivery would be more appropriate, and targeted. More local involvement would decrease community feelings of alienation towards services and officials, and this would increase utilisation, but also impact on general social wellbeing (Zakus and Lysack, 1998).

Participation in health was hoped to enable communities to become more informed, and self aware, which would enable further dissemination of health knowledge, and would enable communities to make choices and be in control of their own health. Also, by having more information and control over their own lives, communities would challenge existing social, political, and economic systems that had constrained them (Rifkin, 1996).

Powerlessness has been conceptualised as a broad risk factor for ill health (WHO, 1986), and participation has been noted as key to enabling empowerment and improving the health of poor and marginalised communities. Some authors feel that participation is one step on the ladder to empowerment (Laverack, 2004), and others feel that participation is synonymous with empowerment. For example, Arnstein defines participation as the categorical term for citizen power. The redistribution of power that enables those, presently excluded from the political and economic processes, to be deliberately included in the future. It is the strategy by which the 'have-nots' can induce significant social reform so they can share in the benefits of the affluent society (Arnstein, 1969). Community participation can be described as a social process whereby specific groups with shared needs living in a defined area actively pursue identification of their needs, take decisions and establish ways to meet those needs (Rifkin et al., 1988). This may also involve evaluating decisions made, and strategies implemented, to bring about necessary adjustments in goals and programmes on an ongoing basis. Community participation is a strategy that provides people with the sense that they can solve their problems through careful reflection and collective action (Zakus and Lysack, 1998).

Paulo Freire's theory of education is often cited as the basis for participatory approaches to development, and participatory action research movements (Rifkin and Pridmore, 2001, Freire, 1972, De Koning and Martin, 1996). If local communities actively participate in collecting, interpreting, owning, and acting upon information, they are enabled to develop a critical consciousness, and have a deeper understanding of their situation. This awareness could help communities become empowered to take action to improve their lives. Freire argued that teachers must engage in a dialogue with learners, and this dialogue should

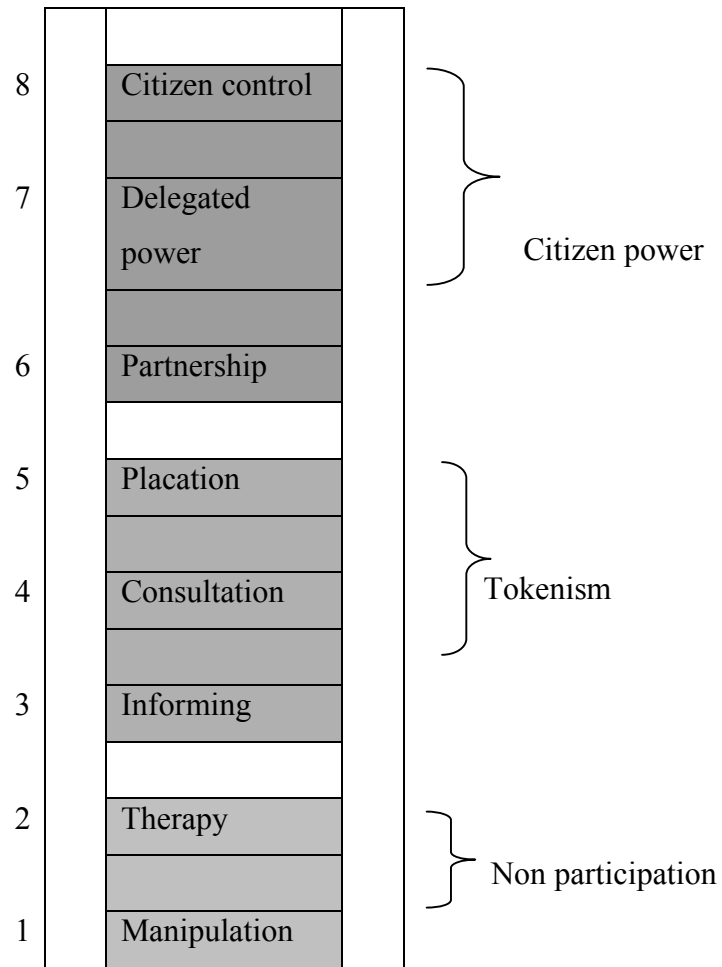
occur in a trusting and equal environment, in which both parties share ideas and experiences and together develop new understanding and awareness (Freire, 1972). Participatory methods - such as rapid rural appraisal (RRA) and participatory rural appraisal (PRA) - were developed by Robert Chambers and other practitioners, to enable community members to communicate what they know and the issues that affect them (Rifkin and Pridmore, 2001). Chambers (Chambers, 2004) argues that these methods will only work if 'professionals' unlearn old habits, and put their knowledge, ideas and categories in second place. PRA methods aim to facilitate the development of appropriate attitudes and behaviours that enable 'professionals' and community members to learn together.

### **5.3 Conceptualisations**

Participation was not clearly defined by Alma Ata, and conceptualisations varied. Its ambiguity is felt to have hindered implementation and evaluation (Morgan, 2001).

Participation was used so extensively that it often became an umbrella term so broad that it could accommodate most forms of development practice (Cornwall, 2000). Arnstein's ladder of participation, although dated, is a useful tool by which to understand different types of participation (Arnstein, 1969) (Figure 10). The bottom two steps on the ladder are the levels when the objective of participation is to enable power holders to educate or 'cure' the participants. In the next two steps there can be tokenistic involvement of communities, whereby citizens may have a voice and be heard, but they have no power to ensure that their views will be heeded by the powerful. Further up the ladder citizens hold some power with increasing degrees of decision-making clout.

**Figure 10** Arnstein's ladder of participation



(Arnstein, 1969)

Some viewed participation as the means to accomplish the aims of a project more efficiently, effectively, or cheaply. Practitioners have experienced difficulties because definitions of participation and expectations about extent of participation have differed among stakeholders (Cornwall and Pratt, 2003). Participation, in the empowerment sense of the word, was often disregarded, and the rhetoric of participation was often used to put a rosy face on business as usual (Morgan, 2001). A review of 18 World Bank documents on health sector reform in South Asia, found that emphasis on community participation was weak, and in six initiatives, participation was used primarily to mobilise resources (finance, labour and time) (Murthy and Klugman, 2004). Zakus found that the Mexican primary health care initiative implemented community participation entirely for its utility in supplying resources and not for democratic or intrinsic values (Zakus, 1998). Participation has also been used by governments to legitimise policy or to diffuse public criticism (Zakus and Lysack, 1998).

#### **5.4 Who participates?**

Just as participation was ill defined by Alma Ata, and has many interpretations, 'community' is also a construct, and its meaning should be considered in the development of programmes (Jewkes and Murcott, 1996, MacQueen et al., 2001). Laverack states that community can be:

- A spatial dimension (place or locale);
- Interests/issues/identities that involve people who otherwise make up heterogeneous and disparate groups;
- Social interactions that are dynamic and bind people into relationships;



- The identification of shared needs and concerns (Laverack, 2007).

Laverack acknowledges that communities are rarely homogeneous groups - within a community there may be social and institutional hierarchies that may be hostile to participatory initiatives. In taking a participatory approach, traditional elites in communities may also have to be prepared to put themselves last, be prepared to work in partnership, and potentially, to be disempowered (Kelly and Vlaenderen, 1996, Chambers, 1997). Deciding who will participate may depend upon time, money and methods. Participation by everyone in a community is usually virtually impossible to achieve or so cumbersome and time consuming that everyone begins to lose interest (Cornwall and Pratt, 2003). Cornwall states that it is beneficial for programmes to opt for optimal participation of a few chosen representatives (Cornwall, 2000). The diversity of individuals and groups within a geographic community can create problems with regards to the selection of representation by its members (Zakus and Lysack, 1998, Jewkes and Murcott, 1998). Representatives may be the more articulate and less marginalised members of a community who may have more time and resources to enable them to participate (including resources such as an ability to speak out) (Guijit and Shah, 1998). Opportunity costs of participation are often higher for the more marginalised. Representatives should be supported by members of the community, and should not be acting out of self-interest (Laverack, 2007). Rifkin suggests defining groups (within communities) that should participate in order to reach programme goals and Cornwall urges practitioners to challenge their assumptions about gender differences, and find out what categories of difference are appropriate and relevant to local people (Rifkin, 1986, Cornwall, 1998). Hildyard et al. present a case study of participatory forestry that did not adequately consider the relative bargaining power of participants (Hildyard et al., 2001). The intervention further marginalised already

disadvantaged groups, and maintained the exploitation and exclusion it sought to tackle. Social psychologists have also offered critiques of participatory techniques and emphasised the importance of taking account of power relations. Group dynamics may lead to 'participatory' decisions that reinforce the interests of the already powerful, and communities may be led to take collective decisions that are more risky (Cooke, 2001). Both of these issues contradict the aim of participation enabling empowerment. The goal of participation should also be considered in deciding who participates – is the goal to promote individual empowerment, or to empower communities?

## **5.5 Challenging power**

External agencies initiating empowerment through participation need to be prepared to engage with local *and* national politics. Agencies should be prepared to challenge power and highlight inequality at all levels. Some have criticised participatory approaches for taking a project based approach or being too focussed on micro level politics (Hickey and Mohan, 2004). They argue that the tools of PRA offer technological or methodological ways of stimulating a kind of participation that does not go far enough to engage with power structures. Challenging power structures is likely to create conflict and discord, and both agencies and communities need to be prepared to deal with this (Woelk, 1992). Agencies and practitioners need to be prepared to support communities in their challenge of power and be committed to long term support. Practitioners have found it unethical to raise expectations, and enable communities to develop a critical consciousness, without supporting them to take action, and deal with the consequences of power struggles. If participation is acknowledged as a dynamic process, not just an end point, the flexibility and long time-frames necessary to challenge power relations often do not fit easily with

academic or development assistance programmes, which can be problematic (Morgan, 2001, Gibbon, 2002).

## **5.6 The need for flexibility**

Although proponents of participation for empowerment may prefer spontaneous participation, initiated by communities, it has been acknowledged that marginalised or disenfranchised communities are powerless to effect participation precisely because they have no power, and that external agents may have a role to play in enabling participation for empowerment (Morgan, 2001, Jacobs and Price, 2003). Yet some agencies have found it difficult to take a less directive role. Balancing community perceived needs with those of health professionals or development workers often proved difficult (Favin et al., 1984). For example, in her review of programmes, Rifkin found that often income, food, shelter and clothing rank above health services in terms of priority needs (Rifkin, 1986). Yet if meaningful consultation about community priorities at programme conception is not carried out, then community members could only ever make the bottom two rungs of the participation ladder (Nichter, 1984). Some are sceptical of the prioritisation process, even in the case of an agency being prepared to take a less directive role. Mosse presents evidence that the articulation of priorities is very likely to be influenced by the perceptions of a community about what an agency can provide (Mosse, 2001).

Tatar found that a biomedical approach to health problems prevented community participation, and others suggest that allopathic medicine is, by its very nature, non-participatory (Tatar, 1996, Morgan, 2001). Socio-cultural and historical traditions of centralised governance, little popular participation, and what Brownlea calls ‘an entrenched

medical dominance' were also evident barriers to community participation (Brownlea, 1987, De Kadt, 1982, Ramiro et al., 2001).

## **5.7 Appropriateness**

Stone criticises the conceptualisation of Primary Health Care and participation as constructs initiated by 'professionals' or 'outsiders', which may limit their cultural appropriateness in poor communities in low income countries (Stone, 1986). Mohan also criticises participation as a Eurocentric concept, and feels that a subtle post-colonialism pervades non-local development workers (Mohan, 2001). Cooke and Kothari also highlight the fact that development practitioners are actively engaged in the construction of a 'participatory development' reality that is amenable to, and even justifies, their existence and intervention (Cooke and Kothari, 2001).

Primary Health Care, is supposed to foster community participation and enable local communities to define their own health needs and initiate ways of meeting them (Stone, 1992). However, PHC came from a concern that providing curative services throughout low income countries would be too expensive, and therefore the range of possible responses to locally defined needs was confined to prevention and health education. By limiting the choices of communities to preventative or health education interventions, PHC was not committed to true participation. In her case study of Nepal, Stone argues that health education was of low priority to local communities and they felt it was irrelevant to their health needs and concerns (Stone, 1986). Zakus and Lysack also feel that the agency of communities is often not recognised, and it should be considered that communities may not wish to participate (Zakus and Lysack, 1998). Pratt also found that in some settings and for

some issues, it is not appropriate to take a participatory approach (Pratt, 2000). An issue may not be an existing concern for others in a community and collective action may not be feasible. Zakus and Lysack also feel that empowerment strategies may be at odds with the notion of community: by empowering some groups or individuals, cohesion and cooperation in a community may be eroded or fail to develop (Zakus and Lysack, 1998).

## **5.8 Measuring participation**

As participation was increasingly stated as a goal or a method of implementation of projects, this necessitated its evaluation. Evaluation increasingly used participatory research methods and particularly qualitative research methods, resulting in their mainstream integration in development evaluation (Morgan, 2001). Measurement of participation is difficult, as it is a dynamic and flexible process, and therefore does not fit easily into traditional evaluation techniques. Also, by its very nature it is context specific and therefore conceptualisations of the utility and generalisability of evaluation are more complex.

Rifkin et al. were perhaps the first to create a model for measuring participation, in order for it to be evaluated in terms that medically trained people could understand (Rifkin et al., 1988). They felt that it was particularly important to convince those with control of resources, that participation was desirable and worthwhile. Numerical indication of the range of activities in which a community is involved or the numbers of people involved is not considered to be an adequate or particularly telling measure of participation. Measures need to capture the dynamics and changes associated with participation and the ability of communities to achieve change, or develop agency (Eyre and Gauld, 2003). Evaluations or

measurements require studying many variables, with different methods to capture the complexity of individual and community change (Wallerstein, 1992). Rifkin's model uses five indicators of participation: organisation, leadership, management, needs assessment and resource mobilisation. Each of these indicators has a continuum of participation, and evaluators can indicate the 'width' of participation on the continuum. Rifkin's model has been utilised widely, and has been further developed, particularly by health promotion and empowerment evaluators (Laverack, 2007). Laverack has criticised the method because it was not carried out by participants or members of a community, as a self-evaluation, and it did not promote strategic planning. He changes the five indicators to eight domains of empowerment, and uses the visual representation tool with community members which enables them to plan to address areas of weakness (Laverack, 1999a, Laverack, 2006b). He uses case studies to illustrate that the evaluation of community capacity acted as a trigger for further action and he wished to use a method of measuring empowerment that could be empowering in itself (Laverack, 2006a, Laverack, 1999b, Laverack and Wallerstein, 2001). Other authors have developed measures of participation or community capacity (Eng and Parker, 1994, Uphoff, 1991). Many authors, of course, develop locally relevant tools, using quantitative, qualitative, or mixed methods approaches that are perhaps more accurate, but more difficult to compare (Caceres, 2006, Bennett and Gajurel, 2006, Kim et al., 2007, Hayes and Willms, 1990).

## **5.9 Participation for maternal and neonatal health**

My review of the maternal and neonatal survival literature described the need for efficacy trials at the community level to enable appropriate and evidence-based interventions.

Community based trials have shown the potential for the efficacy of interventions for neonatal and maternal survival to be tested in community settings. Yet trials have usually focussed on influencing supply side factors (Ensor and Cooper, 2004), tending to involve intervention or treatment by health workers. (Bhandari et al., 2003a, Bang et al., 1999, Boone et al., 2007, Mullany et al., 2006, Tielsch et al., 2007, Bhutta et al., 2008). At present, I am unaware of any other published randomised controlled trials in community settings in low income countries that have tested the efficacy of participatory interventions alone on neonatal survival. Although my review of the literature of health promotion and health education interventions revealed increasing trends towards evaluation of these types of interventions using randomised controlled trials, there is little evidence of RCT evaluation of complex, health education or health promotion community based interventions for health in low income countries. A search of Pub Med revealed 65 hits for a search using terms participatory AND (randomised OR randomized) AND trial. Often, the extent to which interventions have been participatory, or the definition of ‘participation’ was unclear. Some participatory interventions were in fact ‘top down’ where communities were viewed as the passive recipients of an intervention (Bhandari et al., 2004, Kidane and Morrow, 2000). Few studies were based in low income countries. There is a lot of grey literature on community participatory interventions for health but the rigor of evaluations is variable, and more difficult to access. A review of this literature has not been conducted as it is beyond the scope of this thesis.

Women’s support groups are often a participatory strategy implemented to improve community health (Pizurki, 1987, Berer, 1992, Gibbon and Cazottes, 2001, Manderson and Mark, 1997), yet few support groups have been systematically evaluated for their

effectiveness in influencing behaviour change (Green, 1998). Evaluation of groups using experimental designs has been called for by Steel (Green, 1998).

### **5.10 The intervention**

A research partnership between the Institute of Child Health (ICH), and a Nepali non-governmental research organisation (MIRA – Mother Infant Research Activities) has been conducting research to improve neonatal survival since 1992. Technical advisors and Principal Investigators from ICH developed Nepali language skills, and substantial knowledge of the political and social context of rural Nepal. Two technical advisors lived in Nepal throughout the project initiation and implementation. The project was designed incorporating the findings of formative research in Makwanpur District and the ideology, methodology and methods from the Warmi Project (Howard Grabman et al., 1992).

#### ***5.10.1 Theory base of the intervention – The Warmi Project***

The MIRA Makwanpur project was largely based on a project implemented in Inquisivi, Bolivia, called the Warmi Project (women's project). The Warmi project aimed to reduce maternal and neonatal mortality and morbidity by affecting behaviours that influence the outcomes of pregnancy, delivery and the neonatal period (Howard Grabman, 1996). This intervention was implemented in remote villages that were far from a referral hospital, and the area had high perinatal mortality rates of 103 per 1000 births. Women did not usually participate in community decision-making, and in the family, financial decisions tended to be made by men. Maternity care could cost the equivalent of more than six months income. The intervention involved the formation of women's groups in 50 communities, that would



meet at least once a month to function as a forum for learning, decision making, social contact and a diversion from the hard life shared by members (Howard Grabman, 1996).

The project was implemented in the context of the community based integrated rural development methodology. This was based on the premise that long term sustainable development depends on the capacity of community groups to determine local priorities, plan projects, acquire necessary resources and assume responsibility for the administration and coordination of development activities (Howard Grabman, 1996). The goal of women's empowerment was a guiding force in the development of the methodology. Staff and project participants were viewed as beneficiaries, as the project aimed to enable self-development of everyone involved. The role of project staff was to facilitate and help groups in making decisions and taking action, and the project emphasised the importance of respect and belief in project participants to identify and find solution to their own problems. The project was reflexive (staff regularly fed-back from the field, and reviewed methods) and it took a flexible approach allowing groups to determine their own actions.

Groups conducted action research, and developed action protocols for a new cadre of birth attendant, and enabled the training of the new cadre, women and husbands in safe birthing practices. Among other things, they also strengthened referral linkages with the hospital, organised family planning education, and collaborated with NGOs for delivery of family planning services. Over the two-year course of the project, antenatal attendance increased from 45% to 77%, birth attendance by TBAs increased from 13% to 57%, family planning use increased from 0% to 27%, and the perinatal mortality rate fell from 105 to 38 per 1000 (O'Rourke et al., 1998). Although the efficacy of the intervention was not evaluated using

a randomised controlled trial, and the population size was relatively low, the substantial gains in newborn survival made in an area of suboptimal health care delivery, indicated the potential impact of this type of intervention.

The MIRA study protocol also cites the influence of model strategies of participatory forestry in Nepal, (Hobley, 1996, Hobley, 1990, Moinar, 1987) and the successful community based, supply side intervention conducted in Gadchiroloi, India by Abhay Bang and colleagues that showed large reductions in neonatal mortality in intervention areas (Bang et al., 1999).

#### ***5.10.2 The MIRA Makwanpur Project***

Substantial formative research was conducted prior to the implementation of the intervention. The way in which this formative research helped to inform the development of the intervention is addressed in a publication (Morrison et al., 2008a) (appendix 2) and therefore, the following section briefly describes the formative research. The study design, the monitoring system of the project, and the intervention are also described.

##### ***5.10.2.1 Formative research***

Firstly, project entry involved consultations with political leaders, and government health offices in the District and District profiling. A national workshop held in 1998, attended by local community leaders, discussed the aims and design of the study. This was followed by a series of local meetings with members of the District Development Committee and Chief District Officer. A field office was set up in Hetauda in late 1999, from which point local

visits – both formal and informal – increased. This helped to cement links between the MIRA team and local actors such as community leaders, district health services and NGOs. In early 2000, the chairpersons of all the VDCs in the District agreed to take part in the study and provided signed consent. After the project obtained ethical approval, a baseline survey was conducted to collect data on the demography of the population, birth outcomes, and care behaviours. Every married woman of reproductive age was enumerated, and every household mapped. An audit of health facilities was conducted, and qualitative research explored newborn and maternal care practices in ‘normal’ circumstances and in maternal and perinatal deaths.

#### *5.10.2.2 The study design*

The efficacy of the intervention was evaluated by cluster randomised controlled trial design. The trial was designed to demonstrate the impact of the intervention on neonatal mortality rates. The 42 rural VDCs of the district were matched into 21 pairs on the basis of geography, population and ethnicity. 12 pairs were then randomly selected to produce a study area with a population of about 170 000. Finally, one VDC per pair was randomly allocated to receive the intervention and one to act as a control. The study ran for three years, and thereafter, the intervention was implemented in all 24 VDCs to fulfil ethical responsibilities.

The primary outcome was neonatal mortality rate, and secondary outcomes included still birth rate, home care practices, and health care seeking. The study also hoped to improve community awareness of perinatal problems and an increased understanding of ways to approach these problems in the community. This included, knowledge of danger signs in

pregnancy and after birth, knowledge of available services and when to use them, and increased demand for the appropriate services (Institute of Child Health and MIRA, 1998).

Project outputs also aimed to provide descriptive information on the practicalities of managing community interventions and trials, and the development of a generalisable methodology for facilitation and participatory approaches to newborn health. An economic evaluation of the intervention was also completed to inform policy makers about the cost effectiveness of this intervention (Borghi et al., 2005).

Health service strengthening was implemented throughout the 24 study VDCs during the study period, and thereafter was conducted in the rest of the District. Basic equipment was supplied to health facilities, and all cadres of health personnel were given Essential Newborn Care Training. The research team felt that health service strengthening was necessary to bring services to a minimum standard, and it was also ethical to provide some benefit to areas serving as controls. The effect of the health service strengthening was not explicitly evaluated through the study design and surveillance system.

#### *5.10.2.3 Study population and monitoring system*

Women were enrolled into the closed cohort of the study if they lived in the study area, were married, were between 15 and 49 years old (inclusive) and had the potential to conceive within the period of the study. Participation in the study was voluntary, and women were informed that they could opt out at any time.

The monitoring system has been described in other publications (Osrin, 2006, Osrin et al., 2003), therefore only a brief description will be given in this thesis. A minimum of 9 local female ‘ward enumerators’ (WE) were recruited in each VDC to visit every women enrolled in the study to monitor her menstrual status every month. A questionnaire was administered to every pregnant woman at around 7 months gestation, by ‘VDC interviewers’ (VDCI). One month after delivery, a VDCI administered a questionnaire to collect data on care behaviours, and the health of mother and baby. If, tragically, a baby or a woman had died during the perinatal period, a ‘field supervisor’ (all male) administered a verbal autopsy and administered an appropriate questionnaire. Project managers and field supervisors observed a sample of data collection, and questionnaires were checked in the field and in the Hetauda office, before being double entered into a database.

#### *5.10.2.4 The intervention*

A female facilitator was employed in each VDC to convene nine women’s group meetings per month (one per ward). Facilitators were locally resident, literate and had completed the equivalent of a high school education. It was important that the facilitators did not have a health background, and they were given training in facilitation skills. They were supported by field supervisors (one supervisor for every three facilitators), and a facilitation manager. The role of the facilitator was to convene a group meeting (wherever possible) in partnership with the female community health volunteer (FCHV). The role of the facilitator was to strengthen and reactivate FCHV women’s groups, and guide them through a community action cycle. The facilitator received a manual, training and ongoing support in conducting group meetings. A typical group is shown in Figure 11.

Firstly, the aims and objectives of the project were introduced, and then women discussed local maternal and neonatal health problems in the group, and with the wider community. They discussed the reasons for these problems and how they were defined and dealt with locally. Groups then prioritised problems and planned strategies to address their prioritised problems. These strategies were presented at a community meeting and community commitment was sought to help implement the strategies. This process took around one year, and consisted of 10 meetings. Strategies were then implemented and evaluated over the next two-three years. At the time of the trial data analysis (after 3 years), and data collection for this thesis, the majority of groups had implemented strategies but few had completed evaluation. Figure 12 illustrates the community action cycle diagrammatically.

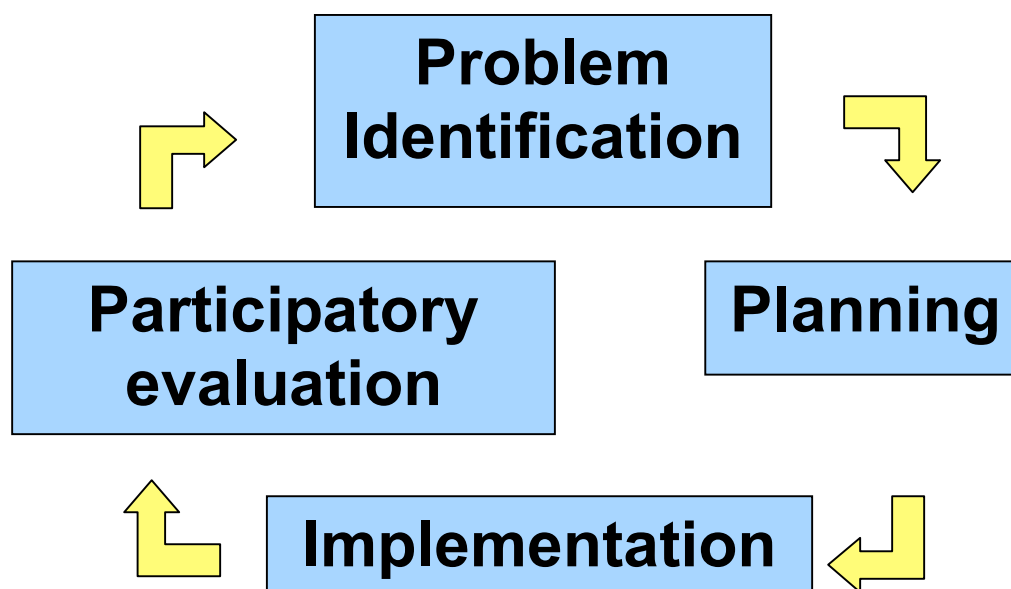
Strategies that were commonly implemented were: maternal and child health funds; clean home delivery kit production and distribution (Figure 13); stretcher maintenance, purchase and management; and raising awareness about maternal and newborn health using a video as a discussion prompt. The facilitation team found that groups often had difficulty linking problems with appropriate strategies, and therefore a perinatal picture card game was developed as a participatory learning tool, promoting discussion about prevention of problems, appropriate home care behaviours, and appropriate referral institutions. Further details about the women's group meeting process, picture card game and strategies can be found in appendix 3 and appendix 4.

**Figure 11 Women's group meeting in Makwanpur**

Photograph by Tom Kelly



**Figure 12 The community action cycle**





**Figure 13 A clean home delivery kit produced by a women's group**

Photograph by author. The kit contains: instructions, a plastic sheet, soap, cotton and gauze, cord ties and a plastic disc for cutting the cord against.



#### *5.10.2.5 Efficacy of the intervention*

The trial results were published in 2004 (appendix 3), and reported that a 30% reduction in neonatal mortality was observed in intervention areas. An 80% reduction in maternal mortality was also observed in intervention areas - although this must be interpreted with caution, as the study was not originally designed to detect changes in maternal mortality.

There was no difference in the still birth rate. Other significant findings were the increase in antenatal care uptake in intervention areas, and an increase in care sought during maternal and neonatal illness from a government health care provider in intervention areas. Women in intervention areas were also more likely to deliver in a health facility, to have a health worker attend their delivery, have the attendant wash their hands before delivery, and have the cord of the neonate be cut cleanly (Manandhar et al., 2004).

Subsequent analysis examined the effect of the intervention on women who had attended women's groups, women who lived in intervention areas, and women who lived in control areas (Wade et al., 2006). This analysis found that women exposed to the intervention were more likely to change from negative care behaviours to positive care behaviours. In intervention areas, women who attended groups were more likely to show a positive change than non-group members with regard to antenatal care utilisation and not discarding colostrums. Importantly, this analysis also found that changes attributable to the intervention were not restricted to specific demographic subgroups. This may indicate that the intervention was equitable. However, unpublished analysis of one month of group attendance does show some patterns among women who were likely to attend groups. Women who were better off, or very marginalised were less likely to attend groups.

Groups appeared to attract illiterate ‘middle poor’ women (Morrison et al., 2005b). An economic analysis of the intervention deemed it to be cost effective according to World Bank guidelines (Borghi et al., 2005).

### **5.11 Rationale for PhD study**

The weaknesses of the RCT method were demonstrated while disseminating trial findings. Policy makers and project funders were interested in process data in order to explain the results of the trial (Grellier, 2004). Therefore, there was a need to analyse the unintended effects of the trial, the mechanisms of change, the effect of the social context on participation in the intervention, and explore how the intervention appeared to work. This thesis aimed to improve understanding of the effect of the intervention, and has explored how individuals and communities in intervention areas have experienced the intervention.

**Research question: How has the women's group intervention been experienced by communities, and what factors may have affected its receipt and the community response?**

#### **Aims:**

- To explore community perceptions of MIRA
- To explore how the intervention has affected community stakeholders
- To explore how the community stakeholders perceive the intervention and their role in the intervention.
- To describe the social context of the intervention.
- To explore how the social context influences the involvement of stakeholders in the intervention and the effect of the intervention.
- To explore the role of the facilitators in the intervention, from the perspective of the community stakeholders and the facilitators themselves.

**Figure 14 A participant in the study**

Photograph by author



## **6 Methods**

### **6.1 Setting**

The intervention was set in Makwanpur District, which is directly south of Kathmandu in the central zone (figures 15 and 16). Makwanpur had a Human Development Index of 0.309 when the intervention started, that was halfway between the highest and lowest in Nepal. The topography of the district is mixed with both hill and plains areas. The district has 43 VDCs and a municipality of Hetauda where the MIRA study office was based. At the time of the study, the District had two public motorable roads.

Detailed information about the study area was collected during baseline research (tables 4,5, and 6). There are at least 15 different ethnic groups in the district the largest of which is Tamang, followed by Brahmin and Chhetri. Tamangs tended to be poorer, engaged in agriculture and to live further away from amenities. The population mainly subsist on agriculture, and 45% of the population has food security for all year. 72% of married women of reproductive age could not read, and 84% had no schooling. Over 90% of households had a male household head (The MIRA Makwanpur Study team, undated).

Detailed baseline information was collected on newborn care practices and deliveries in the three years preceding the start of the intervention. 91% of births in the preceding 3 years took place in or around the home. Birth attendants were usually mothers-in-law, family members, or neighbours. 12% of women gave birth alone. Babies were usually bathed within 30 minutes of the birth (73%), and only 64% were wrapped within 30 minutes of the

birth. Clean umbilical cord care and cleanliness at birth were not routinely practised (Osrin et al., 2002).

Baseline data also shows that there were often delays in recognising and acting on danger signs in the newborn or mother. 40% of women recalled experiencing a significant illness at any time during maternity. During illness, care was usually sought from the shaman, and only 10% sought help from the District hospital, the most common source of allopathic care. Self medication was common, although only 3% reported using both allopathic and ‘traditional’ care (Mesko et al., 2003). Home care practices were influenced by ayurvedic conceptualisations of hot and cold, and care seeking was often delayed. Care seeking was influenced by perceptions of causation of illness, perceived normality of illness, and the importance of limiting birth pollution. Perceived expense of care seeking also caused delays. Qualitative research found that the first delay, (the delay to seek care) in this setting may be the most important to tackle (Mesko et al., 2003). In depth formative research in the district enabled exploration of specific beliefs and practices around maternal and newborn care (Mesko et al., 2003, Tamang et al., 2001).

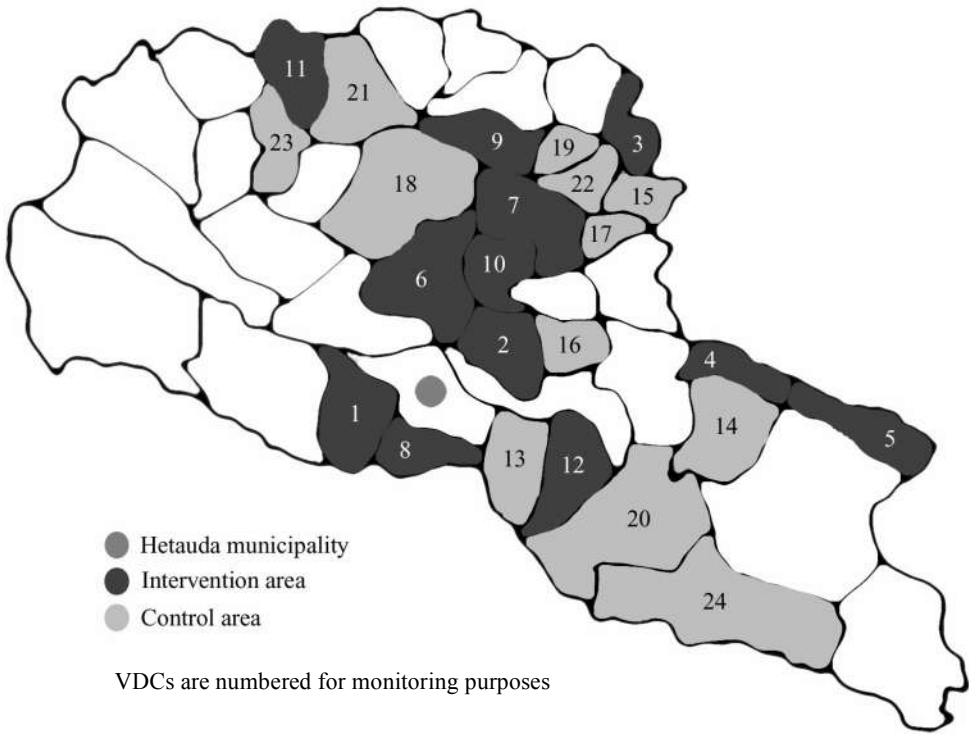
Research for this thesis was carried out in two wards of two different intervention VDCs, and one ward of a control VDC of Makwanpur. They are referred to as Bh, Ch, and Chit to maintain the anonymity of respondents. They are fairly typical of the district, two hill areas, and one plain. Although two of these wards were relatively close to the municipality, data was collected several hours walk from the nearest motorable road. Sampling criteria are described in the following section.

**Figure 15 Map of Nepal showing Makwanpur District**





**Figure 16 Map of Makwanpur District showing study areas**



**Table 4 Religion (Makwanpur)**

Religion	Households (%)
Buddhist	15616 (55)
Hindu	12412 (43)
Christian	322 (1)
Muslim	6 (<1)
Other	20 (<1)

**Table 5 Ethnicity (Makwanpur)**

Ethnic group	Households (%)
Tamang	16037 (57)
Brahmin	3611 (13)
Chhetri	2892 (10)
Magar	1619 (6)
Newar	1069 (4)
Kami	930 (3)
Praja	537 (2)
Danuwar	397 (1)
Pariya	245 (1)
Majhi	236 (1)

**Table 6 Household occupation (Makwanpur)**

Occupations	N (%)
Agriculture	24504 (86)
Waged labour	1976 (6)
Salaried	1124 (4)
Business	772 (3)

**Table 7 Food security (Makwanpur)**

Food security	N (%)
Up to 6 months	5956 (21)
12 months	12806 (45)

## **6.2 Recruitment**

I used stratified criterion sampling for this thesis (Patton, 2002b). Stratified samples are samples within samples, and criterion sampling is when respondents must meet certain criteria. Respondents met the criteria of having lived in communities receiving the women's group intervention, and I then theorised about what types of people would have different perspectives on the women's group intervention, and what types of contexts may affect perspectives and nature of experience. This stratification of the population allowed me to sample different perspectives, and I compared their responses during data analysis. Inclusion and exclusion criteria are described in appendix 1. Snowball sampling was also used to locate men meeting the predefined criterion. Snowball sampling involves locating one or more respondents (or cases), and asking them to identify other respondents meeting the given criteria.

The first phase of data collection was conducted in two wards of two different VDCs (in one ward there is one women's group). Wards were purposefully sampled on the basis of activeness of group (one active, one less active), safety and topography. Activeness of group was defined by field staff on the basis of group motivation, development of strategies and participation in discussion. We did not sample from VDCs where the facilitator was relatively new to the project. Stakeholder groups were chosen on the basis of their potential to hold varied opinions and experience of the women's group intervention. Stakeholder groups were; women attending women's groups, women not attending women's groups (these were split into married women, and mother's in law because the

latter often hold positions of power relative to married women and therefore were theorised to have different perspectives), men, health workers, health volunteers, community leaders, and women's group facilitators. No stakeholder groups were added or omitted after the piloting process. Inclusion and exclusion criteria are detailed in appendix 1.

Research assistants identified participants meeting inclusion criteria. Firstly, women's group members were approached at their meeting, and they were invited to participate in a focus group discussion. The husbands of some of these group members were approached with the group members and invited to participate. These men identified husbands of women who didn't go to the women's group, and researchers visited their homes to ask them to participate. Community leaders were identified by women's group members, and then approached by research assistants. Health workers were approached in local health institutions, and health volunteers were approached in their home and at their monthly meeting in the local health institution. In order to find mothers in law and women who didn't go to groups, research assistants and I walked around the study area making house visits. Local MIRA staff advised the research assistants on populace and paths around the community. One ward became politically unstable during data collection and, for the safety of the research assistants; local MIRA employees accompanied them whilst inviting individuals to participate. MIRA employees were not present during data collection in either ward.

### **6.3 Piloting**

The methods were piloted in order to: assess the feasibility of data collection; develop skills in the research assistants; test the appropriateness of the methods of data collection; refine

the tools used (i.e. topic guides); and estimate the impact of my presence during data collection. Piloting was carried out in 2 Village Development Committees that would not be used in final data collection to avoid contamination of the final data. Table 8 contains the details of piloting.

**Table 8** Piloting

Stakeholder group	Focus group discussion	Group interview	Interview	Observation
Health workers	1	1		
Facilitator			1	
Health volunteers		1		
Women's group	2	1	1	1
Community leader			1	
Mother in law		1	1	
Men		1	1	
Total	3	5	5	1

The main outcomes of piloting were:

- *Data collection should not be conducted by a member of MIRA staff as their involvement may bias the data*

I felt that although I speak good Nepali, my language skills were not good enough to collect data. I was also unable to undertake participant observation (living in villages and attending women's groups) due to employment commitments during the period of this thesis research, and due to the civil unrest. Therefore, a MIRA employee conducted initial piloting with 3 women's group members and one mother in law. It was difficult for the interviewer not to be biased in favour of MIRA, and it was also difficult for respondents to talk openly about their opinion of MIRA. Therefore one Nepali research assistant was recruited to conduct the data collection (RT), and another Nepali research assistant (MM) was recruited from within MIRA personnel, to observe data collection. RT had no previous knowledge or connection with MIRA, and neither research assistant had experience of collecting qualitative data. RT had good written and spoken Nepali and English language skills and MM had Nepali language skills. RT was recruited for her perceived ability to work comfortably in an office and a rural environment, and her good communication skills.

She was also computer literate and can translate between English and Nepali to an adequate standard. Both research assistants participated in qualitative data collection training that I designed and conducted (see appendix 4). This training emphasised the practical aspects of data collection and the aims of the study.

- *Data collection was unlikely to be successful unless research assistants became confident and experienced*

In addition to the training, an extended period of piloting dealt with this issue. Piloting took one month, and role-plays of interviews were carried out before going to the field. I observed data collection and gave positive feedback and constructive criticism. Both MM and RT developed strengths in building rapport with villagers, particularly MM as she lived locally, and RT developed a deeper understanding of the research aims and objectives, became more comfortable with the topic guide, and more practised in listening well and asking open follow-up questions. The detail required in a narrative observation was not well understood by research assistants; therefore we overcame this by using multiple observations of the same event, and discussed these after the observation.

- *My impact on the research process was not substantial with some stakeholder groups.*

This was tested during two pilot focus groups where I was not present, and a third pilot focus group were asked how they felt about my presence (after I had left the room). After an examination of pilot transcripts and discussion with participants we felt that the presence of a non-Nepali westerner on the research process was not substantial. I felt that the benefit gained, (in terms of insight into the nature of the response and understanding of the data)

outweighed any bias or untoward influence on the data collected. I was present during a pilot interview with a MIRA facilitator, which we felt had an adverse effect on data collection, and therefore I was not present during data collection with facilitators.

- *Topic guides were refined and simplified (appendix 5), and a question regarding the security situation topic was added.*

As RT became more familiar with the topic I was able to simplify topic guides and refine or remove questions that were not helpful. I found that respondents were not discussing the security situation. This may have been due to the fact that these particular wards were relatively unaffected, and safe, but respondents may also have been uneasy about these discussions being tape-recorded. Therefore, respondents were asked about the security situation after the tape recorder was switched off and notes were made on return to the office (to prevent the security forces seeing this information at roadside checkpoints).

- *It was logistically possible to collect the data but there may be a problem with language.*

RT experienced problems with language, as she was unable to speak the first language of many participants. Prior to the recruitment of RT, I discussed the possibility of finding a Tamang speaking research assistant who met all other recruitment criteria. MIRA employees did not know of anyone who met all the criteria, and therefore the recruitment process would have been longer and more complicated. It would have also been difficult to give feedback and monitor research skills and consent processes if these were conducted in a language that I did not understand. Therefore, RT was recruited. Although language was sometimes problematic in the field, respondents could speak a good level of Nepali and data were collected in Nepali language. Other methods of data collection, for example the



PEER method, were inappropriate for use in this study (Price and Pokharel, 2005). Chances of social acceptability bias are high with this method, and it is difficult to maintain data quality.

- *Data collection methods were redesigned in the light of unsuccessful pilot focus group discussions.*

During piloting, participants had difficulty expressing their opinions and discussing issues in front of the research assistants and the tape recorder. This was possibly due to lack of trust, a desire to 'give the correct answer', and lack of experience with voicing their opinions. Taking consent seemed to formalise the pilot focus group discussions and increase unease. The tape recorder was very conspicuous and increased feelings of shyness and self-consciousness.

To overcome some of these problems, we took verbal consent and consent to use a tape recorder while inviting stakeholders to participate, as opposed to at the actual time of data collection. During data collection, the tape recorder was placed in an inconspicuous place. Refreshments were provided prior to the focus group, which enabled rapport building, and encouraged participation. A method of data collection using photography was also designed. After reviewing the literature, the method was piloted with husbands, mothers in law, and women's group members. The response of participants to the photography with focus groups was very positive and the data collected was richer.

Data collection methods with health workers were refined, changing focus group discussions or group interviews to semi-structured interviews. This was due to status and gender issues affecting data collection.

#### **6.4 Data collection (phase 1)**

Table 9 presents a summary of data collection. Data were collected in two wards. One semi-structured interview conducted with a government health worker was not tape recorded (due to faulty equipment) and notes were not sufficient to analyse, therefore these data were lost. Focus group discussion and interview data were tape recorded, transcribed in Nepali and translated into English. Observation of focus group discussions and interviews was also carried out and referred to during transcription and translation.

Narrative observation was conducted in Nepali language by research assistants (and was then translated to English) and I wrote notes in English. RT and myself kept diaries during the piloting and data collection phases to document feelings, observations, and reflections about the data collection process. In addition, data were collected through my participation in the observation of the intervention. Whilst living and working in the District centre of Hetauda, I spent substantial time in the communities where the intervention was implemented and I attended many women's group meetings, to observe and advise employees, and to develop the intervention and tools for the women's group facilitators to use. In my working capacity, I have also designed and conducted research to examine specific aspects of the intervention, some of which have been published and are attached as appendices. I attended monthly meetings with field co-ordinators and informally talked with field staff and group members about the intervention.

**Table 9 Data collection phase 1**

Stakeholder group	Method of data collection		
	Focus group discussion	Semi Structured interview	Unstructured Observation
Women's group members	2 (with photos)		2
MWRA not attending MIRA group	2 (with photos)		
Mothers in law	2		
Husbands	2 (with photos)		
Community leaders		2	
Government health workers		3	
Community health volunteers	1	1	
MIRA facilitators		2	
<b>Total</b>	<b>9</b>	<b>8</b>	<b>2</b>
Observed by author	4	3	1

#### **6.4.1 Focus group discussions**

Focus group discussions explicitly use the power of group interaction to gather data and enable participants to explore experiences or topics (Green and Thorogood, 2005). The benefit of this method is that group interaction can facilitate exploration of issues that would not be possible in an interview situation. Groups of (usually) homogeneous participants discuss an issue that they have in common. Even if a group is homogeneous in one respect (they all share a similar experience), attention should be paid to group differences and power relations within groups that are likely to affect discussions. Sampling is particularly key in focus groups, deciding on how to manage discussions among stakeholders that share one thing in common, but may have other issues of internal

group dynamics – local disputes, hierarchies, or gender barriers (Kitzinger, 2000). Group discussion can reduce anxiety of respondents, particularly if the group are used to interacting with each other (Bisol et al., 2008). Focus group discussions may help to lessen the power differential between researcher and respondents, by force of numbers and consciousness development (Kitzinger, 2000, Pini, 2002, Vissandjee et al., 2002). Yet, focus groups can also disempower participants, silencing those that deviate from the dominant or normative response. ‘Devil’s advocacy’ is suggested to avoid the problem of ‘groupthink’ or peer group consensus (MacDougall and Baum, 1997).

The main constraints to conducting accurate focus groups are related to poor skills of the moderator, inappropriate note taking, and inaccurate transcription of the discussions (Maynard-Tucker, 2000). These issues are particularly relevant when researchers are working with relatively inexperienced facilitators, who are bilingual. Training of researchers is important in this circumstance. The practical implementation of focus group discussions can also have difficulties; co-ordinating respondents who are free at the same time, dealing with gate-keepers and social norms, dealing with dominant or reserved respondents, and managing discussions – listening to many voices at the same time, keeping the discussion focussed, and transcription of this type of data (Green and Thorogood, 2005). Good planning, practice, and a flexible approach help to deal with these practical issues (Morgan, 1995, Krueger and Casey, 2000). Discussion tools, or sensory-emotional aids may also be used to focus the discussion (Tamang et al., 2001, Rosato, 2007).

#### **6.4.2 *Photography in research methods***

Piloting revealed some difficulties in the verbal fluency of respondents, and in creating an appropriate, relaxed atmosphere in which to collect data. I discuss the history of photography in research, and then discuss the way that it was used in focus group discussions in this study.

##### **6.4.2.1 *Photography to document and describe***

Visual methods of photography and video have been used in research for many years. A review of 63 articles of indexed in CINAHL (Cumulative Index of Nursing and Allied Health) from 1990 to 2002 found that photography has been used for documentation and surveillance; therapeutic intervention; teaching learning and evaluating performance; as a research method; and in descriptive and instructional literature (Riley and Manias, 2004). The earliest documented uses of photography were in anthropology, when photos were used as early as 1942 in a study of Balinese culture (Mead and Bateson, 1942). Anthropologists used photography to document and describe cultures and practices (Harper, 1998). Researchers have also found the visual image useful in illustration of issues, for example images of a microwave were used to illustrate how it is gendered and how it genders work (Cockburn and Ormrod, 1993).

##### **6.4.2.2 *Photoelicitation***

Sociologists and anthropologists have criticised the colonial and extractive photographic research methods used by earlier anthropologists and have moved towards using visual images in conjunction with discussion and interview (Strangleton, 2004). This is described as an active process of seeking and reaching understanding as opposed to merely

illustrating or documenting processes events or meanings (Harper, 1998). This method has been called photoelicitation, whereby the researcher or participant takes photos of a setting and these are discussed in groups or interviews (Collier, 1967). Visual sociology and visual ethnography use this approach often alongside documentary photography and film-making. Visual ethnography takes a more anthropological approach, seeking to document and capture how culture is represented and expressed (Pink, 2001). Researchers are less likely to falsely interpret images, and participants can more easily understand the research process and realise what the researcher is trying to understand (Harper, 1986, Nelson, 1996). Abstracted photographs of a 'commonplace' situation enable the participant to understand the research and therefore talk more easily about their reality or experience. This approach is particularly useful in phenomenological research where researchers seek to understand human experience. Photography enables participants to contemplate their experience and researcher and participant begin the process of making sense of meanings assigned to contexts or objects. This process of reflexivity and discussion can produce data of much depth.

When using photoelicitation, the photographer can be the researcher and/or the respondent. If the researcher is the photographer, there is an opportunity to discuss commonplace images that the respondent may not have considered photographing. Yet, if the participant is prevented from taking photographs, the research may be weak in validity. 'Native' photography makes it possible to closely approximate how respondents live their lives and make decisions.

#### *6.4.2.3 Photography to access experience*

Many authors have used photography and visual images to overcome communication barriers with respondents, enhancing access to information understanding and experience. Collier was one of the first researchers to acknowledge the value of photoelicitation in overcoming communication difficulties or ‘memory blocks’ which inhibit the flow of information (Collier, 1979). This method has been used with those with intellectual disabilities, and learning disabilities (Jurkowski, 2008, Aldridge, 2007, Booth and Booth, 2003). The lack of ‘verbal fluency’ made photographs a good way to concretise issues to correspond more closely to the thinking of respondents. Visual methods can enable expressions of feelings and experience of health and illness (Bendelow, 1993, Hagedorn, 1994). Cultural and language barriers between researcher and respondents can also be partly overcome through the use of photoelicitation (Banks, 2001), for example in researching homeless children (Hubbard, 1991), exploring the culture of deaf persons (Thoutenhoofd, 1998), researching the culture of farmers (Beilin, 2005), and in research with migrant children and adults (Gallo, 2002, Gold, 1994, Ogilvie and Ryan, 2002). Photography and visual techniques have also been used to elicit views of children and young people (Morrow, 2001), and of black gay men and women in South Africa (Graziano, 2004).

Through photography, a researcher can gain access to a context without being concerned about how the researcher presence may affect behaviour or response (although the camera presence may also affect behaviour or response). This type of insider access can be found in long term participant observation studies – usually of an anthropological nature – which are often not feasible in terms of time and personal commitment of the researcher (Hammersley and Atkinson, 1993). By giving a camera to participants, researchers can

gain access to the environment being researched with relative ease. Researchers and participants can produce a unique data set, which may reveal more about social phenomena than an analysis of textual, verbal or observational data.

#### *6.4.2.4 Photovoice – photography as empowering*

Researchers have often used photoelicitation to access the views and experiences of populations that are less articulate, or study populations who are more difficult to access using conventional or normative research methods. These populations are often the most disenfranchised members of society, and ethical concerns have been raised about extractive research which maintains their disenfranchised status (Castleden et al., 2007). In an effort to address these concerns, some researchers endeavour to conduct research in a more empowering, participatory, action oriented way. Participants are invited to photograph their lives and then photos are discussed with other participants. Photography is used to help participants document, discuss, and analyse their lives, and identify areas that they would like to change. Thereafter, the images are used in communication with decision makers and policy makers in order to work together for change. Practitioners have called this approach ‘photovoice’ or ‘photonovella’ (Wang et al., 1996a).

Photovoice is distinct from photoelicitation because of its focus on enabling empowerment of research participants, and galvanising participants to act upon the research. Photovoice has a theoretical basis in empowerment education, feminist theory, and documentary photography (Wang et al., 1996a). Through the process of documenting their lives through photography, and then discussing the photographs in small groups, participants are enabled



to come to a critical consciousness, or critical awareness about their lives. Freire found that the visual image was a good tool to enable people to think critically about their community, and reflect on their experience (Freire, 1970). By becoming critically conscious of their lives, and developing new knowledge, the community is motivated to act or advocate for change. Through discussion, individuals are enabled to find personal strength and common cause with others in the same situation, and come to a vision of what they would like their lives to be. This vision is shared and projected to policy makers and power brokers, who become educated and better able to understand the reality and experience of communities. Photovoice challenges the established politics of representation by putting people in charge of how they document their lives (Booth and Booth, 2003). Other authors discuss empowerment and confidence development of individuals through learning the skill of photography, and through gaining the ability to formally document their lives. Formal documentation may also enable legitimisation of experience or feeling, and presentation of evidence that policy makers may find difficult to ignore.

Photovoice has become popular, and websites enable access to resources, publications, exhibitions, and have enabled a network for practitioners ([www.photovoice.org](http://www.photovoice.org); [www.photovoice.com](http://www.photovoice.com)). The extent to which photovoice research projects are emancipatory should be presented with caution (Morrow, 2001), as sometimes this is not evaluated within the project, and sometimes the outcomes of the research or project are not known. Some researchers have made efforts to evaluate the participatory or emancipatory nature of their research (Wang et al., 1998, Castleden et al., 2007, Mitchell et al., 2006, Wang et al., 1996b) and acknowledge the difficulties in measuring the effect of photovoice on participants (Wang and Pies, 2004).

#### *6.4.2.5 Ethics and power issues in research using photography*

Photography can be disempowering as well as empowering. If researchers or policy makers set the agenda of what is to be photographed, or if the photos are not owned by the subjects, or photographers, this can be disempowering (Holliday, 2000). Control over distribution and publication of photos is also important, and there is a danger that photographers or subjects may be misjudged if photos are not accompanied by stories or captions (Wang and Redwood-Jones, 2001, Becker, 1998). Photovoice rhetoric is sometimes used to add credibility to agencies that use local people for their own organisational ends (Purcell, 2007). Researchers should be aware of the dangers in raising hopes of change through photography, when little change can be leveraged. As with all participatory research, the ethical dilemma of deciding who participates, and who does not, is also a problem for photovoice. Considering whose voice will be heard, and whose voice will not be heard, is important. Maintenance of anonymity and confidentiality, and the extent to which photography is an invasion of privacy also need to be considered. The ethics of photovoice are discussed extensively by some authors, who make efforts to deal with these issues, but some authors worry that an in depth discussion of ethics may intellectualise the subject and alienate participants (Booth and Booth, 2003, Wang and Redwood-Jones, 2001).

**Figure 17 A women's group member taking photos.**

Photograph by a women's group member while receiving training on how to use disposable cameras to take photos for this study



#### *6.4.2.6 Focus groups with photography*

Nine focus group discussions were conducted. These lasted between two to three and half hours long, and generated a lot of data. Seven out of nine were conducted using photography. Focus groups with mothers in law were conducted with topic guide only, without using photography. This was due to time constraints and their ability to participate effectively without photography. I trained research assistants in the use of disposable cameras and the use of photographs in focus group discussions were piloted. Research assistants invited stakeholders to participate in a focus group discussion (on a different day) and asked those willing if they would like to take photos that would be used during the discussion. They asked the participants to decide how the cameras would be distributed, took the name of a responsible person and trained the participants in using a disposable camera. In each focus group we distributed three cameras with flash, each with the capacity to take 27 photos. They asked participants to take photos of the subjects that would be discussed in the focus group: health, MIRA, and social environment. They asked them to take photos of anything that was important to them, helped them describe something, or represented something they were not able to take a photograph of. After one or two weeks, we returned to collect the cameras, and arrange a time for the focus group discussion. The response rate was high, with all cameras returned, and only one camera was broken during the research process. Two copies of all photos were developed, examined and enumerated, prior to returning to the participants. RT and myself identified any particularly interesting photos, or photos that necessitated particular description by participants.

Whilst conducting the focus group discussion, we asked the participants how they felt about taking photographs and asked if they had experienced any problems or issues. We also asked them if there was anything they were unable to take photos of but wished to discuss. We asked them to split into three groups and gave a film of photos to each group. We asked them to look at the photos and try to put them in the three categories that we would be discussing. Then we asked them to select their favourite, or most representative, or most interesting photos, for each topic and give them to RT. RT had three symbols under which to put the photos (medicine bottle, MIRA logo and a local item), and then she began the discussion by asking which topic the participants would like to talk about first.

Participants were excited by their photos and were often animated and enthusiastic while explaining the story behind their photos. Although the involvement of photography lengthened the data collection process considerably, the increased contact with participants was important in building familiarity and trust, which improved the quality of the data and the extent of participation in the discussion. We also felt that it was important to give something in return for the time taken of participants. We gave one copy of the photos and the negatives to the participants, and retained one copy of the photos. Figures 18, 19, and 20 show a sample of photographs taken by participants, and more photographs are presented in chapter 7, results.

**Figure 18 A ‘coming of age’ ceremony (*Bratabandh*).**

Photograph taken by women’s group member. The boy is having his head shaved.



**Figure 19 A man ploughing his field**

Photograph taken by a man who participated in the study



**Figure 20 Women carrying compost to the fields in bamboo baskets (*dokho*)**

Photograph taken by women's group member





### **6.4.3 Interviews**

Interviews are often conducted to find out what we cannot directly observe (Patton, 2002b). Interviews are conversations directed toward the research topic and vary in the extent to which they are structured (Green and Thorogood, 2005). Some researchers prefer the term 'in-depth' to 'unstructured', in describing interviews with little or no structure that are used in exploratory research when very little is known about the research topic (Britten, 2000). Structured interviews have set questions that must be followed in a specific order in order to generate comparative responses. The benefit of this approach is that a relatively inexperienced researcher can conduct these, the interview is highly focussed, and analysis is less complex because responses are easy to compare. The disadvantages are that the interview is unlikely to reveal any depth of understanding and data is unlikely to be rich, nor full of substantiation (Nunkossing, 2005). The researcher cannot pursue other avenues of questioning, that are of relevance to the participants experience and that were not previously thought of. Therefore, depth of understanding about how a phenomenon is experienced and what it means to respondents might be missed. Semi structured interviews are commonly used, where the researcher sets the topic and directs the interview, but questions are adapted to responses, and responses lead the questioning process to a certain extent (Smith and Osborn, 2003).

Good interview questions should be open, neutral, sensitive and clear to the respondent (Patton, 2002b). Attention should also be paid to the type of question and sequencing. It is usual to start with a question that is easy to answer, that will put the participant at ease and has an introductory nature. This can be called 'funnelling', where questions begin with the

general, and move to the specific (Smith and Osborn, 2003). As with other methods, the researcher should consider how their identity, behaviour, dress, gender, ethnicity etc may affect how the participant feels and the response they give. Power dynamics in the interview context should also be considered, with the researcher being aware and reflexive about how perceptions and feelings of power or powerlessness may affect the interview. Researchers want to enable the participant to feel relaxed and respond to questions. Spradley asserts that the interviewer should exude feelings of: “I want to understand the world from your point of view, I want to know what you know in the way that you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them. Will you become my teacher and help me understand?” (Spradley 1979 pp 34, quoted in (Nunkossing, 2005). Some argue that it is not possible to create an exact replica of experience through the interview, and throughout the process, knowledge and experience is reflected upon and created.

Interviews are usually conducted at the participants’ convenience, in a setting where they are comfortable. Ideally this would be the natural setting, but issues of privacy and peace and quiet may prevent this. The benefits of interviews are that they are relatively easy to arrange, and they enable in depth exploration of a subject. They also allow for more comprehensive confirmation of understanding, which is not enabled in other research methods (Britten, 2000). Another advantage is their ability to provide historical information and reasoning behind behaviours that cannot be observed. The disadvantages of interviews may be that it is difficult to conduct interviews with inarticulate populations, who are less experienced in expressing their views. Also, interviews do not provide access to what people do, only what people say. This is a strength on one hand – we make sense

of the world, and construct the world, through language – yet on the other hand, it is important to use other methods to elaborate on interview findings (Green and Thorogood, 2005).

Eight semi-structured interviews were carried out in this study, without the use of photos. They lasted one to two hours in duration. We tried to introduce the photos taken by other participants as entry points for discussion on two occasions during data collection, but found that they were a distraction rather than being helpful. Also, because the interviewee had not taken the photos, their content did not necessarily match with issues that were felt to be important to the interviewee. Interviewees were usually more confident and tended not to feel uneasy during data collection.

#### **6.4.4 Observations**

Observational methods have been cited as the best method of data collection, as they enable the researcher to observe what people do, not just what they say they do (Green and Thorogood, 2005). By experiencing a setting firsthand, researchers can be open and inductive, and there is less need to rely on conceptualisations of a setting (Patton, 2002b). Researchers are able to better understand the research setting and capture the context within which people have the experience under study. Observation can render visible the routine or the normal, which perhaps interview participants would fail to mention due to their mundane-ness. Researchers can also observe behaviours that participants might feel uncomfortable talking about in an interview or discussion.

There are different types of observation, distinguished by the amount of distance the researcher has to the setting (Gold 1958, cited in (Green and Thorogood, 2005).

Ethnographic or anthropological studies usually use participant observation, whereby the researcher lives the experience they are researching by spending long periods of time in the field, with the study population, joining them in activities, conducting interviews with key persons and embarking on a process of introspection. The aim is to produce an account of a social setting that is faithful to the perspectives of the participants. Researchers experience the phenomena and become more deeply involved with the culture, and analyse and reflect on this (Hammersley and Atkinson, 1993). Observations can also be non-participant, with the researcher collecting data through video recording, or by being in the research setting making notes or tape recordings (Green and Thorogood, 2005). Patton suggests that the degree of researcher participation in observation should be based on thinking about what will yield the most meaningful data (Patton, 2002b). Observations can be structured, which usually generates quantitative data, or unstructured (narrative) where the researcher collects data by writing notes about the setting and interactions of a situation as it happens or directly after they return from the field (Mulhall, 2003). These are often called field notes. Merriam presents an observation checklist that can be used to help guide the researcher to observe beyond the obvious (Merriam, 1998). Observations of focus group discussions can also be used to note important non-verbal communication or events that may have affected the discussion, or as data in themselves. The purpose, scope, length, and setting for the study dictate the possible types of observation.

A weakness of this method is that the presence of the researcher may affect the behaviour and interactions of those being researched. Participant observation aims to minimise this

effect by researchers spending longer amounts of time integrated in the research setting and therefore respondents get used to the researcher presence. If observation is overt then it is difficult to fully overcome this limitation. Another limitation is that notes can present a biased form of data collection. The researcher is making a conscious decision about what to write down, and knowledge is created through the writing process, with interpretations added. Being reflexive and triangulating data can enable the extent of researcher-effect to be documented and considered in analysis and interpretation. There are different approaches to note taking, explored mostly in the ethnographic literature. Mulhall emphasises the need to reflect on how far the self should be used in note taking (Mulhall, 2003). Researchers use different styles: the realist (ethnographer as channeller of information to the reader), confessional (ethnographer's personal reflections are included but separate from information channelled to the reader), or impressionist (the reader is pulled into the account so they have to interpret it themselves). Covert observation raises serious ethical concerns, and it is uncommon that research councils would allow research on humans without their prior consent. Some hold that covert research roles may be justified in certain situations, such as when researching sensitive topics or difficult to access groups (Pope and Mays, 2000).

Participant observation may have been a preferable method of data collection for this study, living in a Tamang household, learning Tamang, attending a monthly women's group, and participating in group activities. Yet as a European, unmarried woman, in her late 20s, I would be limited in the degree of assimilation I could achieve, even after a substantial amount of time in the field. It was also not possible to spend long periods of time in the field, due to my work commitments and this PhD research being part time. Assimilation

would have also been constrained by villagers knowing my role as a technical advisor to the project, and their associations with of access to funding resources through me. I reasoned that without this assimilation, the depth of data collected may equate with using different methods, especially considering my experience living in Nepal. The strengths and weaknesses of my chosen approach are discussed in detail in Chapter 8.

Two unstructured observations were carried out in both wards. Myself and research assistants observed the same women's group meeting in one ward, and research assistants observed the women's group meeting in the other ward. We discussed each observation using a discussion guide to help us consider (among other things), the environment, the people being observed, and the activities being observed (Merriam, 1998). In addition to this unstructured observation, I have conducted other unstructured observations of women's groups for other studies and I have made notes of observations and experiences whilst making field visits in my capacity as technical advisor.

## **6.5 Data collection (phase 2)**

Data were collected in two phases. Preliminary analysis was completed after phase 1 and emergent recurring themes were presented to peers, supervisors and examiners. A second phase of data collection was felt to be necessary, to offer comparative data and add credibility to results for policy makers and other researchers. Therefore I collected data in areas that had not experienced the women's group intervention.

Data were collected in an area where monitoring activities of pregnancies, births and perinatal deaths had been carried out by MIRA in the previous year, but no women's group

intervention had been implemented. The area was purposefully sampled for its safety, hilly topography and relative remoteness. Focus groups were conducted with community health volunteers, and with men. A focus group was planned with married women of reproductive age but logistically this was not possible - there was not a large enough cluster of houses where women lived to make a focus group. To ask women to walk for two hours uphill to a focus group was unreasonable, and therefore two group interviews were held instead. The men and married women of reproductive age were given cameras and discussions were conducted using the same methods as the first phase. A different topic guide was used to follow up on issues occurring in the first phase of data collection and some questions about MIRA were omitted (see appendix 7). RT and MM undertook data collection, transcribing, and translation. I attended all of the second phase interviews and focus groups. Table 10 presents a summary of data collected. The sample was not of comparable size to first phase data due to time constraints.

**Table 10 Data collection phase 2**

	Group interview	Focus group discussion
Women	2	
Community health volunteers		1
Men		1
Total	2	2

## **6.6 Analysis (phase 1 data)**

There is a broad range of approaches to data analysis, and methods of analysis vary by methodological and epistemological approach. Some researchers assert that it is important

to maintain the diversity of qualitative analysis methods, as researchers must respond to the nature of the data and analysis is often a creative process (Bryman and Burgess, 1994). In health research particularly, there have been moves to clarify the analysis process, in part to demonstrate that qualitative research is not anecdotal, but systematic, evidence based, and grounded in the experience of respondents.

In evaluation research, the focus of analysis should be derived from questions generated at the beginning of the research process. In applied policy research, the approach is likely to be more deductive, with the analysis focussed on addressing the research questions of a study (Pope et al., 2000). Deductive methods of manual analysis, can use topic guide headings, or research question headings as the main categories under which to split the data (Krueger and Casey, 2000). Another more deductive approach that I used in this study is the framework approach (Ritchie and Spencer, 1994). It was developed by the Social and Community Planning Research Institute and evolved to meet the needs of applied policy research. This type of research is more targeted towards providing answers, and research is undertaken in short time scales, often by teams of researchers (Ritchie and Spencer, 1994). Although framework is based in original accounts and observations of respondents, analysis begins from the aims and objectives of the study. Policy analysis often follows a process of defining concepts, mapping the range, nature and dynamics of phenomena, creating typologies, finding associations, seeking explanations, and developing new ideas, theories or strategies. Framework starts with familiarisation with the data, and systematically moves through stages of identifying a thematic framework, indexing (sometimes called coding), charting, mapping and interpretation. Framework is an explicit,



systematic approach that can be used by research teams and it is designed so that analysis can be viewed and assessed by people other than the primary analyst.

Transcripts for both phases of data collection were translated into Microsoft Word and then exported into NVIVO software, version 2, for analysis. I carried out the analysis. The framework method of analysis was used for the first phase data, and a simplified process of familiarisation, and coding based on emergent themes was used to analyse second phase data (Ritchie and Spencer, 1994).

As part of the familiarisation process, the data were read and organised under tree nodes (headings); Feelings about MIRA; Feelings about security; Village dynamics; Health service issues; Changes over time; Women's group; Care and care seeking behaviour; Role of NGOs; Women's group strategies; Life/ environment; Participation in the intervention; Role of facilitation personnel; Other (important and less important); and Feelings about MIRA staff. These tree nodes were again split into descriptive child nodes (sub-headings) to enable further exploration of the data.

To test the reliability of the analysis, a random sample of transcripts from each stakeholder group were given to an independent qualitative researcher. This method is sometimes called 'peer debriefing' and is another technique for reducing bias, and checking that interpretations 'ring true' (Creswell, 2003). Due to time constraints, the researcher selected only four of these transcripts and generated themes (appendix 8). These were compared to the descriptive nodes created, and I discussed the data with thesis supervisors. I discussed my thoughts on the main issues emerging from the data, using examples, and we discussed

the words or phrases that would best describe these emergent themes. There was some consensus in themes developed by the independent researcher and the themes I developed. Transcripts and observation data were coded according to those six themes (context, learning and developing, expectations of stakeholders, trust, plurality, barriers to care)

### **6.6.1 Feedback**

Qualitative research can employ ‘member checking’ to check the validity of the findings. This refers to feeding back findings of the study to participants. Few textbooks offer guidance on exactly at what stage and how to conduct member checking, but Bloor 1978 (in (Silverman, 2006)) discusses three different procedures to conduct respondent validation:

1. The researcher seeks to predict respondents classification in actual situations of their use
2. The researcher prepares hypothetical cases and predicts respondents responses to them
3. The researcher provides respondents with a research report and records their reactions to it.

Some authors have warned that respondent validation can be of limited value as findings have been synthesised, decontextualised and abstracted in the process of interpretation and analysis, which can make confirmation or dispute difficult for respondents. Alternatively, researchers must present a descriptive analysis that keeps analysis inappropriately close to the data (Sandelowski, 1993, Morse, 1998). Some have taken a measured ranking approach to respondent validation with literate populations, asking respondents to read findings and tick a box indicating the extent to which they agree with findings (Fuat et al., 2003).

Despite the potential problems with member checking I felt it would increase the validity of the thematic analysis. Participants were ‘fed back’ the main themes from the data, and invited to express their opinion or disagreement after each theme was described. Planned feedback to all stakeholder groups was not possible due to time constraints and the worsening political instability of the country. Therefore, I used purposive convenience sampling and feedback was carried out in both study areas RT (accompanied by MM) gave feedback and discussed the analysis separately with a Village Health Worker (male), a Maternal and Child Health Worker (female), a group of married women of reproductive age and two women’s groups. Member checking was conducted in both areas where data had been collected. I attended member checking with one of the health workers. A feedback sheet (see appendix 9) was translated into Nepali and piloted with colleagues. Respondents were told about each theme, one by one, and asked: “what do you think about this?” The translation of the feedback was altered throughout the data collection in order to communicate better. Feedback sessions were tape recorded (after consent had been obtained). I made a reporting format and RT made reports of each session from the tapes. I listened to one of the tapes to check for bias and adapt the reporting format. A narrative report of the member checking data was written, and a table was made to enable comparison of responses. After listening to the tapes and reading reports of the data, I decided to what extent the respondents agreed with the themes identified in the first phase of data collection. If respondents gave more examples to illustrate a theme this was taken to be strong agreement, if there was very little discussion and engagement was low, it was not possible to find out the extent to which that group of respondents agreed with the thematic analysis. Weight was given to strongly expressed opinions, rather than frequency of response. Despite the limitations and difficulties of member checking (see Chapter 8

limitations), feedback sessions were useful in increasing the validity of the results, and the narrative report was used to inform the analysis.

### **6.6.2 *Charting***

After feedback was complete, the data were charted for each respondent across all themes. This process involves drawing a table (or chart) and writing a description of the views of each respondent for each theme. This enables the researcher to compare and contrast the opinions of each respondent, and look for patterns among the data. Charts were made in Microsoft Word and hard copy was used during analysis. A description of each thematic chart was written, including illustrative quotes and an examination of patterns within the theme. The descriptions and charts were used to find associations across themes, which were used to explain and interpret the data. Through comparing transcripts from different respondents, different types of data, and different methods of data collection, the extent of triangulation can be assessed. Evidence from different sources can be used to build a coherent justification for themes, and triangulation can be used to off-set the weaknesses in other methods, challenging the biases that come from one perspective (Denzin and Lincoln, 2000, Green and Thorogood, 2005). Triangulation can help lead to an improved understanding of the data, as opposed to improved accuracy. Charts also enabled negative or discrepant opinions to be highlighted across respondents. This is a common qualitative technique that helps researchers respond to claims that findings are subjective (Green and Thorogood, 2005). Research questions were referred to during the last stages of explaining and interpreting the data.

## **6.7 Analysis (phase 2 data)**

Although the data were managed in the same way the first phase data had been managed, a full framework analysis was not carried out. Familiarisation and coding was completed, and data were coded under themes of learning and developing, context affecting social development, feelings about MIRA, trust, and barriers to care. Negative, or deviant, cases were also looked for and transcripts were compared for similarities and differences. The themes were very similar to the data collected in the first phase, and there was some triangulation of themes among different respondents. A description of the data is presented in the results section.

### **Research ethics**

The MIRA study was approved by the Nepal Health Research Council and the ethics committee of the Institute of Child Health and Great Ormond Street Hospital for Children, and was done in collaboration with His Majesty's Government Ministry of Health, Nepal. In 2000, the chairpersons of the 24 Village Development Committees involved in the study gave signed consent on behalf of their communities. This study was covered under this consent process. I considered the immediate impact of the research on participants and colleagues, and longer-term potential impacts. The study may raise expectations, and I took efforts to ensure that participants were clear about the purpose and use of this research. Participants in this study were largely illiterate and therefore written consent could not be taken. Participants were provided information about the study, invited to ask questions about the study and participated voluntarily. Participants were aware of my researcher identity when having informal conversations, and as far as possible verbal consent to participate was taken. Sometimes, when focus groups were conducted in common areas,

some participants joined the discussion after consent had been taken. Participants were informed who would have access to the data, and assured of anonymity. These procedures conform to the British Sociological Association guidelines of research ethics (British Sociological Association, 2002).

## Results

**Figure 21 Women's group members making clean home delivery kits**

Photograph taken by a women's group member



## 7 **Results**

Firstly this chapter presents a description of a typical women's group, based on observation data. This includes discussion of the picture card game and implementation of strategies but not the first stages of the action cycle (problem identification and planning together) as these were undertaken before I joined the research team. Thereafter I present the themes from the first phase of data collection and the results of the feedback session conducted with some respondents. Seven themes were identified from the first phase of data collection:

- Context
- Learning and developing
  - Social change and self/community development
  - Dissemination of learning
  - Lack of understanding
- Expectations of stakeholders
- Trust
  - Mistrust of health services
  - Trust of MIRA and non governmental organisations
- Pluralism
- Barriers to Care

This is followed by a description of the data collected in the second phase of data collection in an area that had not received the women's group intervention. Each theme and sub-theme are presented with supporting quotes within the text, and triangulation of the data is demonstrated in the tables by presenting some evidence from different methods of data collection and different stakeholder groups in the different places. For



clarity of understanding, sometimes the voice of the researcher is quoted asking the question. Her voice can be recognised by ***bold italics***. Data from observation notes is presented using square brackets [], as these data were not transcribed.

## **7.1 The women's group intervention**

### ***7.1.1 Describing a women's group meeting***

Group meetings were conducted in many different places, dependant on the weather, and the convenience of group members. Common places include: school grounds, under a pipal tree (a common community meeting place), a forest users group building, a community club building, MIRA office, a front courtyard (*aagan*) of a house belonging to a group member or FCHV, or in the grounds of a village health institution. Group meetings usually took place in the morning, before the main meal, and usually occurred in the first few weeks of the month. Groups sometimes changed meeting place and time, and the next month's meeting time and venue was usually confirmed at the end of the meeting.

Meetings were sometimes changed and cancelled in the month before the next meeting, and facilitators worked hard to please all groups and fit in with their wishes – although this was difficult to co-ordinate meeting times for 9 villages per month if there is little routine.

The facilitator arrived first at the meeting place. She carried the picture card game, register, pen, and calculator, and sometimes the manual (this varied among facilitators). Sometimes the register was left with the FCHV, or group member who brings it to the meeting. On the way to the meeting place, facilitators called out to women to come to the meeting as they pass their houses. Passers by politely asked where they were going and facilitators explain (many times) about MIRA, and the activities of the women's groups. It was roughly, on average, a two hour journey for facilitators to reach the group from their homes. Often facilitators walked alone to meetings, and they were considered brave and hardworking by people they encountered. Group members often expressed admiration for the facilitators,

particularly walking in the jungle (where there is vulnerability to Maoists, army and evil spirits).

Group members assembled gradually, and those that arrived first complained about the latecomers. They talked about their field work, their families, and were very familiar with each other and the facilitator. They often gossiped about a birth or a death. Usually group members had been coming to the group for a year or more (many have been coming since the initiation of the intervention), and if there were any newcomers they stayed close to the person who brought them, and they were subdued. There were usually one or two women at meetings, who did not usually attend (they defined themselves as ‘non group members’). Sometimes women who defined themselves as ‘non group members’ stayed on the edge of the group or sat some distance from the group and observed, as did men or people nearby. Group members were a tight-knit group. Women often brought their children or babies to the group and this caused much disturbance and distraction, but was perfectly acceptable and expected by facilitators and group members. Older children often gathered curiously and play around the group, but teenagers rarely came to the group unless they are married with children themselves. Group members ranged in age from newly married, to older mothers in law. Most of the group members were older and have finished childbearing. It was rare to see many women from the same household at a meeting. Sometimes mother in law and daughter in law attended the same group meeting, but it is not usual to leave a household empty of women, and it is assumed that at least one woman (often the youngest daughter in law) is left to guard the house and serve those that arrive from the fields. Women spoke of the difficulty of leaving their work when coming to the meeting, and this is another reason why it was unusual to see many women from one household at a meeting.

Mothers in law often influenced which woman in her house could go to the meeting. If a mother in law felt that she was too old, she may send her daughter in law in her place. There were not many men in the villages of the district. Many worked overseas, or in Hetauda, or as truck drivers or wage labourers. Therefore, the mother in law was an important decision maker in the households of Makwanpur. In approximately 75% of the women's groups, the local FCHV attended the meeting. It was not always clear that she was different from the other women, although often she talked a lot during the meeting, manages the fund or register, or was seen cajoling other women to answer questions or talk. There were usually a couple of women in the group who appear cleverer than others, or more aware. In some groups these were the most talkative members, and in others these were quiet women who only reveal their knowledge when no one else is talking. They could remember what was discussed in the last meeting, they knew more about maternal and newborn health, and they led discussions and gave ideas. There were disruptive women, who complained to the facilitator that MIRA didn't give anything tangible, and often came to the meeting drunk, and told stories in loud voices. Group members laughed at them, and sometimes welcomed the distraction, although usually, in the end, they tried to keep them quiet and tried to help the facilitator maintain order. Drunken men also disrupted the meeting sometimes, and women felt uncomfortable with their presence. Sober men loitering on the fringes of the meeting appeared to have little effect on the women or the discussion. Women found it difficult to concentrate for long periods of time, and some wandered off towards the end of the meeting, and were distracted by playing with children or talking among themselves. The facilitator did not always speak the language of the women in the meeting, and in these cases it was more difficult for the facilitator to keep the attention of group members and conduct meetings. Language of the facilitator was

considered at recruitment, as was marital status, but often candidates of adequate calibre did not speak Tamang, and were unmarried. Around half of the facilitators were married and half were unmarried. The research team felt that marital status would be important to consider as married women are less likely to move house, and also it may be more socially acceptable for them to talk about reproductive health issues. Marital status was not found to be an important issue, and it was often accepted that a young woman would be educated and knowledgeable. It seemed to be of more importance that she was confident, and could manage discussions and community negotiations. Facilitators appeared to gain respect through their knowledge, employment, and their ability to move around their Village Development Committee.

Meetings usually lasted for 2 hours, or longer. If only a few women assembled, or there was not much time for the meeting, meetings were sometimes postponed or cancelled. The discussion was usually conducted according to the manual, but sometimes if time was running short, some discussions were postponed to the next meeting. Facilitators responded to the feelings of the group members and they knew how long they could keep the group attention. Facilitators often found it difficult to make notes about the discussion while managing it. Facilitators had many reporting forms to fill in for MIRA, and they felt responsible that they should discuss everything that they had to report on. They often used flip chart paper and marker pens to make notes, but these notes were redundant to group members who are largely illiterate. The attendance register was passed around during the discussion, or as women arrived. Many used a fingerprint, or asked a friend to write their name for them. Sometimes the FCHV or facilitator did this. This register was used by MIRA (to examine group composition, and the existence of a 'core' group) and also by the

FCHV who had to report to the health institution on how many women attended her women's group meeting. It is also common community group practice (and office practice) in Nepal to maintain an attendance register. MIRA encouraged the FCHV to view the women's group as her own group, and facilitators and MIRA management undertook continual efforts to co-ordinate the group with the FCHV. In some places personal conflict, a lack of support from the health facility, or long distance from the FCHV's house to the meeting place, meant that the FCHV did not attend the meeting. In a few places where the FCHV was active, they set up a different meeting, but this was not common.

### ***7.1.2 Picture card game***

The research team envisaged that women's groups and communities would link prioritised problems with strategies to address each problem. Strategies would be focussed on addressing factors that prevented that problem from being addressed, as well as causes of the problem. Instead, planned strategies did not obviously 'match' problems – for example more traditional birth attendants were planned to address the problem of infant pneumonia. Often, strategies to generally improve the situation of maternal and newborn health were planned as opposed to being problem specific. Throughout the formative research and problem identification process, the research team had noted a general preference for treatment of health problems in the home. In addition, group and community members expressed a desire to learn how to prevent problems and how to treat them in the home. Therefore, the research team felt it was appropriate to develop a participatory learning tool that would adhere to the general participatory approach of the intervention. Learning would be through problem posing, and choosing among options. Discussion to promote

understanding would also be key. Therefore a picture card game was developed that would be played in groups while they were implementing strategies to address problems.

The game was a packet of small hand held cards of different shapes. Each shape of card represented either a problem (circle shape) a prevention activity (triangle shape), a home-care activities (house shape) or a health institution referral centre (square shape). The cards were pictorial and were developed with technical input from trained health workers, and a local artist. They were extensively piloted with women's groups and adapted accordingly. A manual for facilitators was also developed to accompany the cards. The card game is played in the group by passing round the cards and discussing the pictures. Facilitators present one problem at a time usually. Prioritised problem cards were played first. Then triangle shaped cards are passed around the group and women discuss whether they are appropriate for this problem, and the reasons of their appropriateness or inappropriateness. The facilitator confirms which are the correct cards. Home care and referral cards are discussed in the same way. Sometimes facilitators found it difficult to manage discussion of many cards, so they just chose the correct cards for that problem. This is more didactic, but the game was very popular with women and they really enjoyed playing it. Facilitators reported that group membership also increased after the introduction of this card game, although this may also be partly attributed to increased community awareness of the group after the community planning meeting. The game was introduced after the community planning meeting. The research team completed an evaluation of the game that indicated increased knowledge about danger signs, home care and prevention activities after playing the game. After playing all the problem games, and normal care games, many groups felt that they wanted to play the game outside the group in the wider community. Therefore,

facilitators led discussions of where, when, how and with whom to play the game with group members. Thereafter the team made a tool to help group members remember the order of the cards. A piece of cloth with pockets was given to nominated group members (three per group). One piece of cloth referred to one problem. The cloth had printed shapes of cards on the pockets and relevant cards for that problem were inserted in the pockets. The cloth also had some writing printed (such as the name of the problem), for those women who were literate. Group members were trained by facilitators on their particular problem, and usually went to visit other community groups, pregnant women or family homes to play their game.

### ***7.1.3 Strategy development***

Women's groups discussed how to address their prioritised problems before the community meeting, and then the proposed strategies were presented at the community meeting. Community meetings were conducted before I began working with MIRA, but I was present while strategies were being implemented.

After the community planning meeting, there was a phase where the groups planned, strategy implementation, discussing feasibility and resources necessary. This implementation phase took approximately one year. During this time the groups were also playing the picture card game. Generally, at least 3 meetings were needed to come to a final decision of which strategies to carry out. The groups discussed in depth what they had to do to make the strategy a reality, and how feasible it was, building on previous discussions. It was difficult for the facilitator and supervisor to support implementation of many different strategies, and this is one reason that therefore few strategies were developed, and that these were similar across groups. Groups needed support to take their



ideas forward, in terms of developing confidence and the practical logistics of finding out where to get a stretcher from for example. Many ideas had been suggested by groups and communities, but were not followed through. The amount of support required by the group varied widely, but most groups implemented at least one strategy.

The facilitators and supervisors found that the picture card game was effective in dealing with the mismatch of problems and strategies and helped the women think about what they could do to address problems. Playing the game sometimes delayed implementation of strategies while the facilitator was trying to enable the group to understand the mismatch. The research team felt that the groups generally needed support in how to address their prioritised problems and were in favour of introducing the picture card game at an earlier stage in the 10 meeting process. This would help to develop the knowledge of the group and the knowledge of the facilitator. MIRA gave facilitators Essential Newborn Care training to facilitators six months after the intervention started, and supervisors reported that earlier training of facilitators would have helped the facilitators be more confident, and perhaps more appropriate strategies would have been implemented. At management level, a decision was taken to delay training of facilitators to prevent them from being ‘educators’. Supervisors were encouraged to remember the aim of the participatory process, and management level felt it was more important to encourage action even if it appeared not to match problems.

#### *7.1.3.1 Access to community resources*

An essential part of the implementation process was following up on money and support pledged in the community meeting. Formal applications for money often had to be written, and problems occurred when newly elected persons who had not attended the community

meeting had to be approached for money pledged by their predecessor. The political instability made implementation difficult as promised money was sometimes inaccessible or unavailable. In some cases the Village Development Committee provided money to some groups and not others. The reasons for this were because the ward chairperson did not pledge money, or the ward chairperson didn't come to the community planning meeting, or the groups were unaware that community resources were available and therefore they did not ask for them.

The strategies decided upon in the community meeting were not written and signed by those who had pledged to support which sometimes made follow-up difficult. VDC chairpersons were given a summary report of the meeting by supervisors that was beneficial in maintaining good relations. MIRA had planned that supervisors should attend regular VDC meetings, to brief local leaders and keep abreast of community activities, but they found this difficult as they were not made to feel welcome, the agenda was not often relevant, and then local political structures were dissolved due to the civil conflict.

#### *7.1.3.2 MCH fund*

Initiation of a Maternal and Child Health Fund was recommended and implemented by a large proportion of groups. This may be partly due to the fact that in the majority of VDCs, saving credit schemes operate, and therefore the women and community were familiar with funds being set up by groups. The groups felt they needed support from MIRA in managing the fund. Support was obtained from a local bank and a representative trained senior staff and supervisors. MIRA senior staff wrote a draft MCH fund management policy, and training was given to all facilitators by senior staff, supervisors and the bank representative. All facilitators were given a draft policy. Women's group members

nominated management committee members, of which at least one was literate, and occasionally sought committee members external to the group. Facilitators and supervisor's co-ordinated training of committee members in respective VDCs and refreshments were provided.

Groups decided their own policy of how to manage the fund and how often money will be collected or given. Groups were managing MCH funds using a register and data was collected on how they were set up, where the money is from, how much is used, what the money is used for, how long it takes to return the loan.

#### *7.1.3.3 Stretchers*

NGOs such as PLAN and International Red Cross have provided stretchers to health facilities in the past. When the community and group suggested stretchers as a means of addressing the prioritised problems, MIRA encouraged the groups to investigate the status of stretchers in their ward. This took some time, but many were located, and money and/or materials were gathered for their repair. Those that did not need to be repaired were often taken under the management of the group, to enable easy access even when the health institution was closed. Where there was no stretcher, the group gathered funds and/or materials and either bought these with the help of MIRA (as they had to be brought from Kathmandu), or made the stretcher from local materials (wood and cloth, or *dokho*). Groups were encouraged to raise awareness of the stretcher and its location in the ward and some groups levy a charge for usage. Some groups had management committees.

#### *7.1.3.4 Clean Home Delivery Kits*

Initially, one group suggested making Clean Home Delivery Kits, but many groups have implemented it since the community planning meeting. Initially, materials were sourced and priced by the supervisor and facilitator, and the senior team consulted with MIRA president (a paediatrician) for advice on kit contents. The group decided on design and cost of the kit and met together as a group to package the contents. Contents are: 3 cord ties, plastic coin, new blade, cotton wool, gauze, plastic sheet, soap and instruction leaflet. At first the instruction leaflet was used from the MCH products kit, but when this strategy became more popular among groups, the pictures from the picture card game were used and piloted, with additions of a breastfeeding picture and a handwashing picture. The instruction leaflet also has the MIRA logo and a space for the mothers group to write their name and date. The group decide their own distribution strategy, which has included distribution through FCHV and TBA, through group members, through local shops, and through health institutions. Since the first group made the kit, supervisors and facilitators have told other groups about this strategy and this strategy has been implemented in every VDC. Some groups have cut up large lumps of soap, some used pre-packaged (believing it would make the kit more appealing to consumers), some groups have used recycled plastic not in the coin shape. Some groups were keeping the cost as low as possible, only selling it enough to recoup the cost of making it, and others are putting profits into their MCH fund or Stretcher fund. Concerns were raised by MIRA president and health institution staff with regards to sterilisation, and therefore group members boiled the contents before they were packaged, and briefed purchasers to boil the contents prior to usage. Kits were also sold to families who didn't live in the study area.

#### *7.1.3.5 Film*

The Institute of Child Health sought funding from DFID to make a film about community based newborn care, and worked with Indian filmmakers on the script and editing. The film was made in Makwanpur District, and was made into a VCD (Video Compact Disk). Each facilitator was given a copy to use in their Village Development Committee. It lasted 20 minutes long, and begins with a description of the present situation for women in rural Nepal. Care of a newborn immediately after birth is also shown, and there is discussion of newborn danger signs and preventative health care. The video has been shown in all wards where there is electricity, a television and a VCD player. In some cases security problems have disrupted plans to show the film, preventing the gathering of large number of people. Usually group members locate a household with video equipment and a television and request their help. In a few place, a VCD player owned by MIRA was taken to nearby areas to enable show the film. The group advertised the film show, and planned where to show, and whom to show. MIRA provided some guidelines to encourage the groups to discuss issues raised in the film, and advertise their strategies and encourage women to come to the group. The film has been shown multiple times in the same place. Usually, the film was played in its entirety and then group members explained the work of the group to those gathered. There was usually little discussion about neonatal illness, and more discussion about the group meeting, and the strategies. Audiences and groups enjoyed watching the film and it is a good way to involve community members in the work of the group. The song from the film has also been used by the groups – sung at the women's festival (teej), played in buses, and sung at group meetings.

## Context

**Figure 22 A woman carrying fodder for her animals**

Photograph taken by a women's group member



**Figure 23 A Nepali family**

Photograph taken by a married woman of reproductive age who participated in the study



**Figure 24 Boys having their morning meal in the fields**

Photograph taken by a man participating in the study





## 7.2 Context

Respondents were asked to talk about village life to gather information about the context in which the women's group intervention took place. Data are presented describing different aspects of society and how they affect society and social interaction. Table 11 provides further evidence.

### 7.2.1 Poverty and the difficulties of living in marginalised areas

The majority of respondents were engaged in household work, agriculture, and animal husbandry. All respondents felt that life was tough, and that everyone in the village had to work hard to have enough to feed and clothe their family: *"we spend time ploughing the field, weeding the maize field, grazing the cattle. Even to have a meal twice a day is difficult...we work 24 hours, we have no time to rest even in the house."* (M, FGD with photos, Bh).

Respondents discussed problems of landslides, particularly in the hilly area, Bh: "the water source was swamped by the landslide last year...and the water was blocked by that" (WG, FGD with photos, Bh). Respondents in the flat area (Ch) were concerned about their water supply: "the main problem of this village is water" (WG, FGD with photos, Ch). Those in Bh particularly felt despondent that they had limited opportunities to improve their lives: *"I earn a living on the landlord's land. The yield is divided half for the landlord and half for us. It's necessary to survive by doing hard work." ... "I don't have good farm land. It is necessary to survive. This place is full of sorrow."* (MIL, FGD no photos, Bh)

### 7.2.2 Gender division of labour

Although both men and women were engaged in agriculture, a division of labour was evident in other activities. Women spent their time collecting firewood, grass, and water as well as tending to animals, preparing and cooking meals, and caring for the children: *“some go to graze the cattle” “Some cook food, some cut grass. Some collect firewood”* (HV, FGD no photos, Bh). When there was no agricultural work, the men worked ‘outside’ as drivers, or labourers, or in carpet factories: *“brothers spend their time doing their own business, by working” “Some of them spend their time by driving and some by doing labour work” “Anyway mostly women work in the farm compared to men”* **Why?** *“They go to earn money. We fetch the water, cook food for the children do the work of farming”* (MWRA, FGD with photos, Ch).

In one area (Ch) most of the female respondents felt that women work harder than men. Health volunteers in Bh also shared this view. Respondents talked about the invisibility of housework and how it was unfavourably compared with men’s work which often brings in money *“those who go outside bring one bundle of grass, and ask: ‘what did you do in the house?’” Those who stay in the house cannot get time to drink a cup of tea”* (HV, FGD no photos, Bh). Women felt that men had an easier life than women: *“In comparison to men, women do lots of work”* (MCHW, I, Ch). They felt that if men were earning money then they would spend their free time having fun, playing cards, and drinking alcohol *“If men become free then they play cards and play carom board. They don’t gather for the work of development. That is a bad thing”* (MWRA, FGD with photos, Ch). This was contrasted with women who were perceived to have to work all the time and find it difficult to find

time to go to learn and develop their skills in meetings or community groups *“although there is lots of work, while coming (to the group) we have to come by leaving all the work”* (WG, FGD with photos, Bh). Women said that they were more active than men, and more interested in development and change *“even men help, but in comparison with women, men are not active”* (MCHW, I, Ch)

### **7.2.3 Gender roles**

The care of pregnant women and newborn babies was considered the traditional domain of women. Men were sometimes embarrassed to discuss this issue (see also barriers to care), and were sometimes reluctant to come to ward meetings called by the women’s group, or discuss the work of the group. They felt they had little to contribute to this ‘female area’: *“only a few fathers attend...after it is known that the video show is going to be shown then the fathers say to the mothers to go (laughs). They say, ‘what types of things are told there?’ The fathers say ‘we are not going there now’ ...and tell the mothers to go”* (F, I, Ch).

Particularly with regards to education, respondents felt that discrimination against girls was decreasing: “Right now there is no discrimination; there was a lot of discrimination before.” “We didn’t get the chance to study before because of the discrimination and we are uneducated. If we were educated than we could get a job” (WG, FGD with photos, Ch). Men in one area also mentioned that they have learned that it is good to send daughters to school as well as sons, and they said that household work is equally distributed between girls and boys.

#### **7.2.4 Context of political conflict**

Several respondents mentioned the political insurgency and intimidation. Male health workers (who walk around the villages regularly) particularly felt vulnerable and threatened by Maoists, and other respondents complained about army intimidation and not being able to access health care at night because of the government imposed curfew.

Maoist and army activities also made it difficult to involve men in the work of the group:

*“It’s because of the state of emergency. It has been difficult from both sides (army and Maoist)”* (F, I, Bh). Large gatherings were against the law during that time, and groups of men were particularly vulnerable to suspicion by the army: *“the time and situation is not good to gather (everyone) in the same place...All the brothers don’t come to the meeting. They say, ‘it is not our meeting and only sisters should attend’. It is difficult to motivate them”* (F, I, Bh)

#### **7.2.5 Violence and domination within households**

Many respondents, particularly in Ch, mentioned violence within households and their village. Domestic violence was linked to alcohol and gambling, and particularly in Ch women said that men found it acceptable to beat their wives, finding them deserving of this treatment. *“When the sisters of our group went there to tell them not to play cards, what he said to us was: ‘husbands feed (women) by earning money so when they become insolent (rude, impolite) they need to be beaten by their husband.’ He said like that.”* (MWRA, FGD with photos, Ch). There were several reports of Maoists retribution attacks on men who had been drinking or beating their wives, and women told stories of their campaigns

against card playing and men who beat their wives. *“One of the villagers of ward no 8 used to drink alcohol. He used to work as a carpenter. He often beat his wife because he was drunk. She was beaten even though the children were grown up. Because she couldn't tolerate the suffering she committed suicide by hanging herself in the tree of her own field. Then the Maoist came to know about that and in revenge they tied the husband on the bottom of the same tree where his wife committed suicide and punished him by breaking his hands and legs”* (VHW, interview, Bh).

Trafficking of women for sex work was discussed, and the rape of a woman was also described. Polygamy was described as a problem for women in one area; *“the main problem of this area is that people do double marriage. Sisters come to ask for help from organisations.”* (CL, interview, Ch). Household dynamics were described, revealing male control of the household, and domination over some decision making by the mother in law. There were also examples of women fighting back against this domination, and supportive male behaviour, which supports other data about social change; *“my husband doesn't stop me from going anywhere”* (HV, FGD no photos, Bh).

#### **7.2.6 Fatalism**

One respondent, a health volunteer, referred to fate several times in her interview. This respondent talked about the pointlessness of taking medicine or going to the hospital if it was time for a patient to die (*kaal ayo*). She also talked about the water availability problems in terms of fate, believing that *‘it is our destiny not to have water’* (HV, interview, Ch). Foreign and Nepali scholars have written about the Nepali belief in fatalism and its effect on Nepal. The belief that the future has already been written by the

gods (and little can be done to change this) has been considered a hindrance to the socio-economic and health development of Nepal.

### **7.2.7 Ethnicity**

Ethnicity also affected the way that villagers interacted with each other. Caste discrimination was still evident: *“If bhote and chepang (marginalised castes) had come then I would have asked them to clean the cattle dung”* (HV, FGD no photos, Bh), and language differences prevented communication between groups. This affected the work of the group where the facilitator did not speak the same language as participants: *[VDCf asks them to speak in Nepali language and to listen to her]* (WG, Obs, Bh). Homogeneity of caste was considered to be a hindrance to development, and respondents felt that where there was a mix of different ethnicities, more ideas can be discussed and villagers become more motivated to work for change. This is discussed further in the theme ‘learning and developing’.

**Table 11 Context**

Subtheme	Evidence	Respondent	Method and place
Poverty	<i>"They are doing very hard work. No one in this village sits without doing work. The people of this village work the whole day"</i>	M	FGD with photos, Ch
	<i>"We need to go up the steep hill to cut the thatch, and we don't like that." "I feel worried walking in the steep hills." "If we don't go at that time then we cannot stay in the house because the roof leaks in the rainy season (laughs). At that time I feel sad and I think about whether I can leave this place."</i>	MWRA	FGD with photos, Bh
Gender division of labour	<i>"we work for six months in the field and the rest of the time, men go outside to work and women do the household work"</i> <i>"outside means that some are drivers, and some are labourers. Whatever work they get, they do"</i>	M	FGD with photos, Ch
	<i>"Do boys and men work like women? No they don't"</i> <i>"Only women and girls do work, men don't look at work."</i>	MIL	FGD no photos, Ch
	<i>"Husbands earn money. We do work at home the whole day. We need to do more work than him but we don't earn money. They earn and get cash. Who gives the money for our household work? No-one sees our work, and we don't get support to do our work. If we say anything to our husband then he says, 'I have earned money, what have you done staying inside the house?' But the ones who stay at the house have to do a lot of work."</i>	WG	FGD with photos, Ch
Context of political conflict	<i>[in ward number five there was a women's group before but the Maoists didn't allow them to conduct community meeting there, so right now there is no women's group]</i>	HV	Obs of FGD no photos, Bh

(WG, women's group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)

## Learning and developing

**Figure 25 Women playing the perinatal picture card game.**

Photograph taken by women's group member of the picture card game being played with women who do not attend MIRA women's group.





**Figure 26 A baby being delivered at home by a traditional birth attendant**

Photograph taken by a women's group member. The traditional birth attendant is a women's group member and the photograph shows the plastic sheet of a home delivery kit that the baby was delivered on to.



**Figure 27 Photograph taken by a women's group member of a woman breastfeeding her baby under a mosquito net**



### 7.3 Learning and developing

This theme illustrates the way in which respondents felt they learn and develop an understanding of new concepts. Sub themes detail the way in which respondents develop an understanding, how they gain knowledge and information, and the difficulties of encouraging those who are old fashioned and unmotivated to learn. Quotes sometimes illustrate more than one aspect of a theme, and more evidence is presented in tables 12, 13 and 14.

#### 7.3.1 *Social change and self/community development*

##### 7.3.1.1 *Social change and its causes*

Respondents felt that their society was changing and that social awareness was being developed. Respondents often compared present behaviour and village social environment with that of previous generations: *“they say that this did not happen in their time. They say that change has occurred according to the time, and say that this (newborn care) should be understood”* (F, I, Bh). The societal changes were considered to be positive and were attributed to:

- Education: *“now they (villagers) have changed their mentality, they think that education is the main thing”* (MCHW, I, Ch);
- Increased exposure to information through radio and television: *“as is said in the radio, it is not good to keep the son in the lap and the daughter in the hillside.”* (M, FGD with photos, Bh);

- The influx of organisations and community groups that have provided training, resources and new knowledge: *“they give training. They arrange seminars to discuss about the forest, need to do so and so, if we destroy the forest then we may have these problems...”* (CL, I, Ch), *“we were provided with things. They have given us training about how to use those things”* (FCHV, FGD no photos, Bh).

### 7.3.2 Type of social change attributed to organisations

When referring to changes from previous generations, there appears to be a change from being carefree and unconcerned about learning new things, to becoming motivated and eager to learn: *“They (women) used to stay at the house before but now they go outside and lots of NGOs and INGOs give lessons to everyone”* (MCHW, I, Ch). Respondents attributed this change to involvement in organisations: *“Before, they (women) used to be engaged only in their own household activities like cutting grass and firewood and they had not understood very much about other things...Because they attend meetings they have started to understand about things.”* (F, I, Bh) Respondents reported changes in their own behaviour, and a realisation of problems. This was accompanied by an increase in knowledge of how to deal with problems, which further increased confidence: *“They were scared and didn’t know anything. It was so difficult before but right now lots of changes occur here...all that happened because of the various training...by the organisation.”* (MWRA, FGD with photos, Ch).

Several respondents reported that, previously, there were no illnesses, or that communities were unaware of illnesses: *“The babies were not caught by diseases. They were well, but now people say ‘if we cut in that way (with sickle) then the baby may be caught by the*

*disease’’* (HV, I, Ch). Due to the increase in illness (or increased awareness of illnesses) there was a belief that behaviour must change to deal with this, and new knowledge was needed. An appropriate and available place to obtain knowledge was in community groups or with organisations: *“If women didn’t want to do the household work they could go to other places...actually they go to the meeting to find out something, that’s why we think (that meetings don’t take women away from household work).”* (M, FGD with photos, Ch) Respondents generally felt positive about working with organisations: *“the organisations also help. I feel that if a man is given knowledge then he may be improved. So, it is good in comparison with before. They (villagers) do understand matters”* (MCHW, I, Ch).

All respondent groups, apart from MWRA of Bh, had received training or education from non governmental organisations, or had some experience of becoming socially aware through interaction with non governmental organisations: *“through the training we came to know that we shouldn’t hate her (an HIV positive woman)...nobody says anything to her now, she also goes to the training.”* (WG, FGD with photos, Ch). Social change appears to be experienced more by women than by men, or women were more vocal about social change than men. This is also demonstrated in the theme of context.

### ***7.3.3 Social change attributed to MIRA***

Respondents reported that women’s confidence had been developed through their involvement with MIRA, and they were now less embarrassed than previously: *“they are eager to know about something and they were not hesitating to discuss their problems. Those women who didn’t want to tell about their problems before, were interacting with each other.”* (CL, I, Bh). MIRA groups were felt to be a source of support, and a place for

learning and sharing knowledge: *“I wish to learn that is why I come (to the group)” I also come here with friends. This group is very good, I can hear new things, I can meet with friends. Otherwise, we didn’t know before that we could get medicine in the health post. We have learned lots of things after joining the group.*” (WG, FGD with photos, Ch).

Facilitators also reported some change in their social status and some personal development after starting to work for MIRA: *“We have got the chance to learn, likewise for group members. Before, I only knew that I should be clean, but I didn’t know that the baby too should be clean. Although I had two babies I didn’t know (smile). At that time I was ‘alaare’ (immature, irresponsible, unaware). Anyway for this third baby, because of the training provided, I did whatever I learnt. I think I have also changed”* (VDCf, I, Bh)

#### **7.3.4 Self and community development through increased interaction**

Organisations and their staff were usually external to the village or were more mobile, interacting with many people from different places. This was generally viewed as positive: *“we didn’t know how to farm the land for 12 months a year. We just came to know about this a few days before, when (an organisation) came here to tell us about it...Because we think that no-one can do anything, we sit like this, we can’t move forward nor backward”* (M, FGD with photos, Ch). Respondents believed that if you were able to walk outside of the immediate village, then your likelihood of having new and different knowledge is much greater, and this knowledge should be shared with others: *“Women shouldn’t depend on others, we shouldn’t stay inside the house. We should come out of the house and we need to learn some things. Whatever we know, we should tell others. We need to share with each other.”* (CL, I, Ch).

### ***7.3.5 Dissatisfaction with organisations***

Although there was an overall positive feeling about working with organisations, a few stakeholders voiced some dissatisfaction. Organisations were accused of not co-ordinating with each other, and not providing enough information about their aims and objectives. There was also some mistrust of organisations, particularly from men. Some issues of mistrust may also be associated with the externality of the NGO worker, and this is discussed in the theme of Trust.

During feedback of thematic analysis, respondents confirmed the overwhelming positive feeling towards organisations, and disputed issues of mistrust (see part 2 of this chapter, feedback of results).

**Table 12 Social change and self/community development**

Sub theme	Evidence	Stakeholder	Method and Place
Social change through education	<p><i>"I am not educated, because my father didn't teach me at that time. I wish to educate my children even though I am not educated.</i></p> <p><i>"My granddaughters also go to study. There is nothing better than to be educated.</i></p> <p><i>...It's good if people are educated. If they are educated then no one is able to dominate. When someone asks 'what is your name?' Then they can tell them. That's very good."</i></p>	MIL	FGD no photo, Bh
Change promoted through media, television	<p><i>"Before the people were superstitious. They used to believe in anything. Now people believe less than before. One thing is ... through different communication media like television, people have come to know about various types of disease. Because of this reason, the feeling of 'the patient must be taken (to hospital)' has developed. This revolution has occurred."</i></p>	F	I, Ch
Social change through involvement with organisations	<p><i>"(We) can get knowledge about lots of things. The things that we don't know, if our other friends know about that then we can share. (We) can know about everything. The formation of mother's group and women's group is good. The mothers groups that MIRA has made are also good. Whichever group and organisation that our PLAN (an INGO) has made is also good."</i></p>	MWRA	FGD with photos, Ch



Sub theme	Evidence	Stakeholder	Method and Place
Social change attributed to MIRA lessening embarrassment	<i>“I liked their interaction very much...What I liked was, one or two women were speaking openly. It might be due to the impact of the picture cards that they were speaking openly...While going to the meeting (pause for a while) I have seen an improvement in (women’s) consciousness”.</i>	CL	I, Bh
	<i>“(group meetings) have made an effect. Before, there was more miscarriage. The villagers sisters didn't know about its cause. In the intervention VDCs, the WE asks why women have more bleeding and miscarriage. The sisters of this village don't say about the pregnancy because they feel embarrassed (shy). They carry heavy loads and bleeding occurs. They sit without telling anyone about it. When this happens they need to go for a check up, or when they have white discharge, but they don't go because they are feeling embarrassed (smiling). So, the foetus will miscarry. Now, they meet with us and ask us for help when this happens. They ask without feeling shy, like: ‘where should we go as this has happened?’ We will also tell them whatever we know, like we refer them if necessary. The effect is good.”</i>	F	I, Bh

Sub theme	Evidence	Stakeholder	Method and Place
Learning in MIRA group	<p><i>"We are given lessons. Given lessons by saying do this and that and you need to go there."</i></p> <p><i>"I like whatever they have taught us."</i></p> <p><i>"During pregnancy, there might be swelling or what I don't know."</i></p> <p><i>"Hands, legs and back bone might swell up."</i></p> <p><i>"I heard about the breech delivery might happen."</i></p> <p><i>"Some women have the problem of retained placenta."</i></p> <p><b><i>What do you think about the difference before and after going to the meeting?</i></b></p> <p><i>"Now, they (wife) are more clever than before".</i></p> <p><i>"They (wife) have become more clever".</i></p> <p><b><i>In what activities? For what activities are they clever?</i></b></p> <p><i>"They say such and such work should be done during this time."</i></p> <p><b><i>Such.... such means what?</i></b></p> <p><i>"Like taking the patient (feeling uneasy) to the hospital. If I need to say about the internal matter. Like what happens during menstruation. While during pregnancy how it should be. They teach to take such and such medicines during such and such time and suggest to go for check up."</i></p>	WG	FGD with photos, Bh
		M	FGD with photos, Bh
Self and community development through increased interaction	<p><i>"Where there is a presence of many people, lots of things are discussed. That's why the decision is not the same. Anyway, now there is a little bit of change."</i></p>	F	I, Bh
(WG, women's group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview)			

### 7.3.6 *Learning and disseminating information*

This theme is called ‘learning and disseminating information’ because respondents talked about gaining new knowledge from MIRA, and other women in the group, and talking to others about information they had learned: *“We came to know after joining MIRA group. Now we are giving training to others. We didn’t know before...”* (WG, FGD with photos, Ch). Most of this data refers to MIRA groups, as opposed to other community based groups. Every stakeholder group discussed an aspect of dissemination of learning, but most of the data in this theme is from women’s group members, women’s group facilitators, and health workers. Some men acknowledged that the women in their families had learned from the MIRA women’s group, but were reluctant to talk about what they had learned: *“MIRA organisation has taught that this will happen (smiling) in this time, and they tell that we should do this work during this time...like taking the patient to the hospital (feeling uneasy), if I need to say about this personal matter...”* (M, FGD with photos, Bh). They appeared embarrassed, and this was likely to be caused by social norms dictating that pregnancy, childbirth and the care of the newborn being the domain of women, and men’s involvement should be limited. *“This is the matters of women (smile), they don’t tell us.”* (M, FGD, Ch). Therefore there may have been gender specific dissemination of knowledge.

#### 7.3.6.1 *Hierarchy of learning, and cascade of information*

Employees of MIRA, particularly the WE (Ward Enumerator) and the facilitator, were mentioned as sources of knowledge and information. The WE tended to disseminate only information about EPI (expanded programme on immunisation) to women, whereas the

facilitator was part of a hierarchy of learning - the facilitator gave knowledge to the women's groups members, who then discussed what they had learned with their friends and neighbours: *"We disseminated the information to everyone through the women's group, like tetanus, or whatever the programme is. The group members spread to their neighbours...it is spread out to the community through the group."* (F, I, Ch). There was evidence that group members disseminated knowledge about:

- EPI (expanded programme on immunisation) *"Now, mothers group members give suggestions about immunisation and also about health. Maybe because of this the numbers of patients have increased. I am very grateful to the mother's group members for that. In the beginning people didn't come to take immunisation."* (MCHW, I, Ch).
- The work of the group: *"they ask 'what did you do in the meeting, what did you learn by going to the meeting? Because they were saying that, we conducted a ward meeting to make other people understand."* (WG, FGD with photos, Bh);
- Clean delivery: *"group members have made villagers understand that the dirty things affect them. They even told the villagers to keep the bedding neat and clean before delivery. We have found that they even teach these things too."* (VHW, I, Ch).
- Antenatal check-up, and referral for newborn and maternal health problems: *"if the baby doesn't suck milk or breathe or cry it should be taken to the hospital immediately. We tell them everything. We tell them through showing the pictures."* (WG, FGD with photos, Ch).

### 7.3.6.2 *Strategies as facilitating dissemination of knowledge, and building community networks*

This knowledge development and dissemination was supported through co-ordination with local health personnel (the Village health worker and Maternal child health worker), and was reinforced by radio and television: *“Whatever we say the radio also says the same thing, we may forget lots of things so if we listen to the radio then we may remember whatever we have forgotten”* (WG, FGD with photos, Bh). Group activities, and the implementation of strategies, enabled this dissemination of knowledge, and were discussed by all respondents, particularly the home delivery kit: *“I give them suggestions like saying, ‘if the delivery kit is used then you won’t get caught by diseases. Women come to take whenever they need them.”* (WG, FGD with photos, Bh). Although only one out of the two groups that we sampled had made a kit (Ch), some other groups in Bh had made kits and these were being distributed throughout the Village Development Committee.

Other group activities also appeared to increase contacts with other community members or community groups and facilitate the dissemination of knowledge;

- Collecting for maternal and child health funds: *“we told them (household members) that we wouldn’t give money for other diseases just for problems of mother and infant”* (WG, FGD with photos, Ch);
- Collecting money for making or buying a stretcher: *“the women’s group came to ask for money in our meeting on 29<sup>th</sup> as they didn’t have sufficient money (to buy a stretcher)”* (MWRA, FGD with photos, Ch);
- Showing of a film (‘the birth of a baby’, made by MIRA in the local area): *“after showing the video to pregnant women, those who didn’t go for check up, they started to come for check up”* (WG, FGD with photos, Ch);

- Playing the perinatal picture card game: *“we say to them, ‘we will teach you something through these pictures and they come. She (pointing) tells us about retained placenta”* (WG, FGD with photos, Ch);
- Discussion with villagers at a community meeting: *“we conducted the ward meeting to disseminate the information about the fund and stretcher as others do not know about it”* (F, I, Bh).

These activities appear to have enabled villagers to be involved in the work of the group, and enabled discussion about maternal and neonatal health. The picture card game was felt to enable increased understanding or more effective learning of group members: *“the picture card game is good for those (women) who go to the group regularly. We came to know about whatever we didn’t know before. We suggest that (women) go to the meeting as there are very important things to know.”* (HV, FGD no photos, Bh). Facilitators in both areas mentioned playing the game with villagers who were not in the group, and the more active group (Ch), had started to play the game with villagers thus widening its effect: *“We show the pictures while in (other) group meetings” “They don’t understand how the foetus lies...while showing the picture and by looking at the picture they have told us they thought that the baby lying with its head downward is abnormal.”* (WG, FGD with photos, Ch).

This group had also discussed moving their meeting place to enable more people to participate and learn from the group: *[she suggests it will be easy if they conduct the meeting in different place...other group member supports her saying the people in the next cluster of houses don’t know anything so the meeting should be conducted there]* (WG, Observation, Ch).

### Table 13 Learning and disseminating information

Sub theme	Evidence	Stakeholder	Method and Place
Gender specific dissemination of knowledge	<p><b><i>What do you think, what have they come to know after joining the meeting?</i></b></p> <p><i>"Like 2 or 4 things."</i></p> <p><b><i>Can you tell what are that 2 or 4 things? (Laugh)</i></b></p> <p><i>"Sisters didn't tell us before about that."</i></p> <p><i>"Like, they don't tell at home about what they came to know."</i></p> <p><i>"According to their talking style, we can identify they found out about 2 or 4 matters. Even we don't ask them 'what have you done?'"</i></p> <p><b><i>Can you tell me, what matters do they talk about and how do you identify that they came to know?</i></b></p> <p><i>"Go and ask with your wife! (All of them laugh loudly)."</i></p>	M	FGD with photos, Ch
Hierarchy of learning and cascade of information	<p><i>"We tell them that they shouldn't do that. If the placenta is retained then let the baby suck the breast, pass the urine. We tell them about the household treatment."</i></p> <p><i>"The main cause of retained placenta is... I heard that urine in the bladder block the placenta. Laxmi sister (supervisor) and Miss Ganga (facilitator) have told us that. Let the postnatal mother pass urine. If it doesn't work than let the baby suck the breast."</i></p> <p><i>"People didn't do this before." (WG, FGD with photos, Ch)</i></p> <p><i>"Although (MIRA) doesn't give anything it provides lessons. They teach us first and then we tell the sisters of the village. We have to say, 'we have been taught these things and you need to do this.'"</i></p>	WG  HV	FGD with photos, Ch  FGD no photos, Bh

Sub theme	Evidence	Stakeholder	Method and Place
Hierarchy of learning and cascade of information	<i>“What I feel is that (MIRA) assembles the female group and tells them something. Anyway, they come to know. (MIRA) has shown the way to the blind (uneducated). That’s all.”</i>	M	FGD with photos, Ch
	<i>“We didn’t know about anything before. We didn’t know about the FCHV of the village. Didn’t know about the TBA when the meeting started, then after that we came to know about FCHV and TBA.”</i>	WG	FGD with photos, Bh
	<i>“(group members) have made (villagers) understand that dirty things affect them. They even told the (villagers) to keep the bedding neat and clean before the delivery. We have found that they even teach these things too”</i>	VHW	I, Ch
Dissemination of knowledge about Clean Home Delivery Kit	<i>“Now, in the village, people come to ask ‘do you have delivery kit?’”</i>	HV	FGD no photos, Bh FGD with photos, Ch
	<i>“They didn’t know before but now they come to ask.”</i>		
	<i>“we sent 30 kits with the TBA and FCHV...”</i>	WG	
	<i>“They say they don’t need to go and buy it in another place. It has become easier for them. They say, ‘you make us understand about things as we don’t know about things.”</i>		
	<i>“...We take and after giving kits, they ask ‘what is this?’ (We say): ‘This soap is not for the baby. This is for those who conduct delivery to wash their hands. This plastic is should be spread (on the floor). This blade is used to cut the navel of the baby. These three threads are needed to tie (the cord). We tell them everything.”</i>		



Sub theme	Evidence	Stakeholder	Method and Place
	<i>“They (clean home delivery kit) are kept in both of the member’s houses. In the ward, two of the members have taken care of it. They also distribute to others... We give the information about it to all the sisters and they come themselves to take them.”</i>	F	I, Bh
Learning through the video and mobilisation by facilitator	<i>“the video has been shown lots of times on the colour T.V.”</i> <i>“Those who are going to give birth and that... (Interruption)”</i> <i>“Shouldn’t carry heavy things, like this. Everything has been shown on there, I heard about that but I didn’t go there (to watch the video).”</i> <i>“Ganga (facilitator) was telling me to go there.”</i> <i>“I was called there so I went there.”</i> <i>“Ganga (facilitator) was telling me to go but I didn't get time to go.”</i>	MWRA	FGD with photos, Ch
	<i>“the room where the delivering woman is kept should be clean...all those things are shown (in the video)”</i>	MWRA	FGD with photos, Ch

(WG, women’s group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)

Sub theme	Evidence	Stakeholder	Method and Place
Dissemination of knowledge by group members using picture card game	<p><b><i>Here are also photos, look at this.</i></b>  <i>“This is the training given to us about retained placenta.”</i>  <b><i>What were you doing at that time?</i></b>  <i>“She is pregnant. We are showing her. We were giving suggestions to her to go to hospital”</i></p>	WG	FGD with photos, Ch
	<p><b><i>What do you say, through these pictures how are people getting advantages?</i></b>  <i>“They are very good.”</i>  <i>“We didn’t know before that the cord should be tied in three places.”</i>  <i>“We used to give a bath to the baby on the same day. Maybe because we gave a bath to our baby on the same day that they use to have 'ghyar ghyar' (a sound produced by infants with pneumonia). Until 3, 4 and 5 months they couldn’t suck milk. They might have pneumonia. We have told everyone about this. The people of the village say, ‘oh! we didn’t know about this before, now we have come to know about this and we will tell other people about this too.”</i>  <i>“We tell them keep two knots on the side of baby and one knot on the side of placenta (during cord care). While we taught them they told to us we didn’t know about this before, we used to make one knot and cut (pause for a while) even my family also did this.”</i></p>	WG	FGD with photos, Ch
	<p><i>“If we show the pictures, then women understand”</i></p>	HV	FGD no photos, Bh

(WG, women’s group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)

### 7.3.7 *Lack of understanding*

During data collection it became apparent that villagers divide the population into those who understand (*bujne jane manche*) and those who don't understand (*nabujne manche*). This segregation is not easy for an outsider to define, and requires knowledge of individual behaviour, attitudes and interactions with others in villages. Roughly those who 'understand', are considered clever, and those who don't 'understand' are considered to be not clever. If my definition of *bujne jane manche* is correct, more stakeholders who 'understand' were unintentionally sampled than those who are defined as those who do not 'understand'.

#### 7.3.7.1 *Frustration with those who do not understand*

Most of the data about 'not understanding' was from those who considered themselves to 'understand' (group members, community leaders, health workers, health volunteers, and MWRA who were members of other community groups). They talked about their frustrations with those who do not understand, and distinguished these people from themselves: "*we not only attempted to bring her to the group, but also for the antenatal check-up. Every effort was made but that person wouldn't come*" (F, I, Ch). They felt that those who do not understand were making life difficult for those who wish to progress or develop, and were preventing others from moving forwards. They were also blamed for not helping themselves, or failing to try to progress: "*the placenta didn't come out because of their own foolishness. It might be that her mother in law didn't love her. She pulled the baby out and the mother died*" (VHW, I, Bh). These types of people do not see the value of

coming to meetings, or being involved with NGOs, and those who understand found it difficult to convince them of the value of meetings: *“If nothing is provided to eat, just the meeting being conducted, then no one comes. How can those type of people understand?”* (WG, FGD with photos, Ch).

The frustrations of those who understand trying to convince those who do not understand may indicate that it is acceptable in this context to persuade people to act differently. *“We tell them this is for our health. This is good for our village. This is good for us. This is to improve our health. It is dirty for those who don’t understand, it is good for those who understand.”* (WG, FGD with photos, Bh). There were also a few narratives of success about women persuading men to act differently, or a facilitator persuading a group member to use the health facilities as opposed to a shaman, or group members persuading women to come to groups that were previously reluctant to come. Where there is contact between villagers it may be appropriate, and considered caring, to tell others what they should do: *“We need to move forward and they will come behind us...”* *“We need to make them understand.”* (WG, FGD with photos, Ch)

#### 7.3.7.2 *Apathy and lack of motivation to learn*

Respondents recognised that opportunities were limited in villages, but felt that people who do not understand did not take advantage of the opportunities that were available. Some respondents accepted this blame to a certain extent, and confirmed the interpretations of others: *“We don’t know anything”* *“We are like idiots”* (MWRA, FGD with photos, Bh). Whilst others felt they were victims of their circumstances and did not have the opportunity

to interact with others from outside the village; *“I don’t visit the village because we are farmers that’s why we don’t know about this.”* (MIL, FGD no photos, Ch).

### 7.3.7.3 Tradition

Those who do not understand were felt to favour traditional beliefs, and not trust new methods or new information: *“Some people still remember traditions, maybe they don’t try to understand. They say ‘we cut the cord of our children with Khukuri (knife), but the people of today say that they need to sit in a meeting’”* (WG, FGD with photos, Ch). These conservative opinions of those who do not understand sometimes prevented women from attending meetings: *“...”Those who understand, they stay in the meeting, those who don’t understand said that they don’t like to listen about dirty things, they feel irritated...some men who came to listen said ‘you go and attend the meeting to talk about this kind of thing?!! You don’t need to go to the meeting!’”* (WG, FGD with photos, Ch). While discussing a maternal and neonatal death that happened in their village, the women’s group of Bh discuss the issues that define a family that ‘don’t understand’. They hold traditional beliefs and abide by social norms, the delivering woman is of low status in the family, they don’t know about the dangers of long labour, they delay going to hospital, and they are embarrassed about delivery;

*“they (in-laws) might think about their own (past) time, those who can give birth, they give birth, otherwise they die”*

*“this is a matter of embarrassment (shyness, laaj), and that people don’t have knowledge”*

*“people take to the hospital when (the person) is about to die”*

*“they don’t understand, there was no one to talk about that (going to hospital). Everyone said, ‘we gave birth after so many days (labour), and it didn’t make any difference’”*

*“That’s why, by depending on what other people said, they kept her (the delivering woman) in the house”*

#### *7.3.7.4 Limited context and experience*

Some respondents felt that the insular nature of life in a village prevented people from developing an understanding or encountering new knowledge: *“Some men are employed, (we are not employed). We don’t know anything, we are unable to read and write. We do agricultural activities. From morning until evening we are involved in agricultural activities.”* (M, FGD with photos, Bh).

**Table 14 Lack of understanding**

Sub theme	Evidence	Stakeholder	Method and Place
Frustration with those who don't understand	<i>"those simple people don't try to understand things, they don't apply in their behaviour. They continue with whatever they are doing... I used to give them advice...to do both types of treatment (with shaman and doctor) then they say 'ok' but they don't believe in doctors. They don't use them, it means they don't want to investigate about new things... As a whole, they don't try to find out, or they are not eager to know about new inventions. They are satisfied with whatever they are doing. This is a bad side. For example; in matters of health and hygiene, education, however it is going on they let it go on in the same way."</i>	CL	I, Bh
	<i>"they (some villagers) don't give interest"</i> <i>"they don't come to receive medicine either, they don't come to receive vitamins. Three days ago the woman nearby my house gave birth, I didn't know about that. I came to know about this two days later"</i>	HV	FGD no photos, Bh
	<i>"In comparison with people from down, upward people don't know anything"</i> <i>"I have told them lots of times to join the group, but they don't want to join"</i>	WG	FGD with photos, Ch
Apathetic, unmotivated to learn	<i>"We are living like illiterate and dumb (people)"</i>	MWRA	FGD with photos, Bh I, Ch
	<i>"Although we are living near the town, we are living like people who live in the jungle."</i> <i>"One of the bad (things about here) is that people don't try to understand."</i>	MCHW	

Sub theme	Evidence	Stakeholder	Method and Place
Apathetic, unmotivated to learn	<p><i>“We also have a women’s group. The women of other places are getting lots of facilities. Some of them are getting training about sewing and knitting.</i></p> <p><i>“They have done lots of things. Nothing has been done for us.”</i></p> <p><i>“Maybe people from here cannot speak, because of that reason.”</i></p> <p><i>“We just go (to the meeting) there; we don’t get any facilities from there”</i></p>	MWRA	FGD with photos, Bh
Traditional	<p><i>“She is giving birth (and not asking her husband to use family planning) not because she doesn’t already have a baby. What this is, is that the people of the village don’t understand these things. After doing family planning, a man cannot pray to god, he becomes 'Khashi' (castrated animal that is not used for animal sacrifice because god will not accept castrated animal)”</i></p> <p><i>“Right now I have become Shrestha. I got married with Shrestha (and had an intercaste marriage). While going to the group in the place up there, what the people said was, the wife of Ram Newar comes here, we should break her leg, we should kill her while waiting on the way.”</i></p> <p><i>“Those who understand, they have a check-up but those who don’t understand they don’t have a check-up. A few days before in the day-time, at 10 o’clock, a shaman was doing work for Hira sister”</i></p>	<p>MWRA</p> <p>CL</p> <p>HV</p>	<p>FGD with photos, Ch</p> <p>I, Ch</p> <p>FGD no photos, Bh</p>



Sub theme	Evidence	Stakeholder	Method and Place
Traditional	<b><i>Don't understand means, what don't they understand?</i></b> <i>"they say whether is it mothers group or father's group, 'people didn't need this before, but now people from this age, say they have to join the group. They say like this."</i>	WG	FGD with photos, Ch
Limited context and limited interactions	<i>"One thing is there is the homogeneity in the caste. In this VDC more than 75% of people belong to Tamang caste. Due to the majority of people being from one (emphasis) caste, people have the same opinion. They don't understand things so much. But in places where there is mixed caste, those people understand properly. They actively perform whatever task. But due to the presence of only our caste, people don't take part actively, I think so."</i>	F	I, Ch

(WG, women's group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)

## Expectations of stakeholders

**Figure 28** Children going to fetch water

Photograph taken by a married women of reproductive age who participated in the study



**Figure 29 Women queuing for water**

Photograph taken by women's group member



**Figure 30 A community meeting called by an NGO**

Photograph taken by a man who participated in the study



## 7.4 Expectations of stakeholders

This theme presents data about respondents' expectations of NGOs to provide services and infrastructure, and dissatisfaction with MIRA for not meeting these expectations nor providing tangible benefits in study areas. Further evidence for this theme is presented in Table 15.

### 7.4.1 Type of expectation

Villagers tended to depend less on government and expected non-governmental organisations to assume a provider role. Respondents felt that not only should non-governmental organisations provide knowledge, they should also provide:

- Services: *"We have a problem of water" "If you (MIRA) can bring water then it would be good"* (MWRA, FGD with photos, Ch)
- Incentives for attendance at meetings: *"It if it is said that there is a party in the school today then everyone comes, leaving all their household work. If nothing is provided to eat, only a meeting is conducted, then no-one will come (laugh)"* (WG, FGD with photos, Bh)
- Infrastructure: *"even the school was improved by (an organisation) this year. To maintain the (Buddhist temple and the church) is not possible by villagers because of the economic condition. It would be good if any organisations could help"* (M, FGD with photos, Ch)
- Facilities: *"we are getting maize seed and fertiliser from (that organisation). I heard that for this year, the seeds of fruits and ladies finger would be provided"*

(MWRA, FGD with photos, Ch) *“I think they might provide seeds. If we demand then they provide vegetable seeds.”* (WG, FGD with photos, Bh)

#### **7.4.2 History of aid**

This expectation may be based on a history of development aid in the study area, as many NGOs have been working to provide buildings (schools, health posts), loan facilities, training and small enterprise opportunities for women (giving seeds, goats, chickens etc). They have also provided emergency relief and ambulance services. MIRA was not exempt from these expectations, even though it has never provided the kinds of services and infrastructure given by other organisations: *“Kaam chha, daam chhaina (work yes, money no), this is our main problem...the organisations can help. For example MIRA can help us”* (HV, FGD no photos, Bh). Consequently, respondents reported hearing dissatisfaction, or feeling dissatisfied themselves, with the lack of tangible inputs from MIRA.

#### **7.4.3 Tangible benefits synonymous with work**

There was an expressed preference for organisations that give tangible benefits to villagers, and some respondents felt that if an organisation did not provide something tangible to the village, they were not working. MIRA was unfavourably compared to other more ‘giving’ organisations by all respondents: *“PLAN has invested money in making school building, drinking water, and HIM Rights organisation works about AIDS...MIRA hasn’t done any work in the village until now. It hasn’t invested in any field, that’s why no one knows about it.”* (M, FGD with photos, Ch). Men and MWRA in both areas said they were unable to express an opinion about MIRA because they haven’t seen any work that it has done: **What**

***effect has (MIRA) made?*** “Other work hasn’t been carried out yet. Only that (ward meeting)”. “We don’t know”. “Until now, we don’t know.” (M, FGD with photos, Bh).

There were also reports of MIRA providing some services: “All the things carried out are good...(WE) asks all over the village and after taking the report she brings back the medicines for the disease from which they are suffering. Sometimes she will tell you to go with her” (MIL, FGD no photos, Bh).

Research assistants felt that men had low expectations about what they receive through this thesis research, and this affected their response: *[while they saw Mangala and I they were maybe thinking ‘they are not going to give us anything’, so they took the discussion lightly]* (M, Ob notes from FGD with photos, Ch). Men were particularly dissatisfied with MIRA, complaining that they hadn’t been called to a ward meeting: “we don’t know anything” “we didn’t get any information” (M, FGD with photos Ch) and they felt that MIRA does not meet the needs of men: “it just assembles the women, it only looks after women, maybe it doesn’t look after men” (M, FGD with photos, Ch).

#### **7.4.4 Difficulties of working without providing tangible benefits**

Facilitators and group members complained that because MIRA has not given anything tangible, this helps to justify the attitude of those who do not ‘understand’, making it difficult to increase group membership and persuade villagers about the value of going to the group: “They might have come to the meeting thinking they could get something, or could get to eat...they went away...” “They say ‘if we do the work for the whole day then we could be able to finish lots of work, but in the meeting we don’t like to listen about the dirty matters” (WG, FGD with photos, Bh)

#### ***7.4.5 Irritated by questions and lack of service***

Female respondents reported that their peers were irritated by MIRA's regular enquiries about their menstruation and family planning status. This irritation was sometimes due to a feeling of embarrassment or shame about pregnancy, which is common in Nepal: "*They say 'we feel shy and scared'*" (MWRA, FGD with photos, Ch). Yet more commonly, women were irritated because they did not receive anything in return for the information that they gave: "*We are not getting any advantages.*" "*She just asks and goes*" (MWRA, FGD with photos, Bh). They found it pointless that MIRA regularly visited their house to ask after their health, but could not provide them with medicine for any health problem that they were experiencing: "*women say: '(MIRA) asks about menstruation, whether it is ok or not. Why don't they provide medicine if it is not ok?'*" (HV, FGD no photos, Bh). Although male stakeholders were not irritated to the same extent as female stakeholders, many respondents suggested that it would be beneficial for villagers if ward enumerators carried medicine or were trained to give treatment and conduct deliveries: "*MIRA goes to every house, so if the staff of MIRA can provide general treatment or means of family planning then it will be good*" (CL, I, Bh). Observation during data collection also triangulates these findings, as we heard ward enumerators being asked to buy and carry medicine, and attend births.

#### ***7.4.6 Area for improvement, not dissatisfaction?***

The expectation that MIRA should provide tangible 'development' or service to the villages was often stated in the form of a suggestion for improving the way that MIRA worked:



***How could MIRA work better?*** *“If possible by providing fortified flour to the pregnant women free of charge, they would be happy about this.”* (VHW, I, Bh). Some respondents that had requested the provision of services by WE’s were often those who felt the women’s group meeting process had been very positive and beneficial. During feedback of initial analysis, respondents suggested that we put less emphasis on dissatisfied views or unfulfilled expectations. A limitation of the feedback was that it only included one group of respondents who were less satisfied with MIRA.

**Table 15 Expectations of stakeholders**

Sub theme	Evidence	Stakeholder	Method and place
History of aid	<p><i>"We are poor so we don't have money. Who provides? No-one from outside comes to help."</i></p> <p><i>"From where is money given to the poor?"</i></p>	MIL	FGD no photos, Bh
Dissatisfaction with MIRA, and perception that only tangible development is work	<p><i>"What the people of the village say is...if the work which cannot be seen by the eyes it hasn't been done, then what has been done by so and so...(Interruption)?</i></p> <p><i>"by so and so organisation".</i></p> <p><i>"What has been done by so and so organisation? They have just done the work of asking', they say like this, and what I tell them is: 'it's not like that. Right now they are learning what are the problems of the village. This is their investigation time'. Women use to ask 'what have they given? They haven't even given a headache tablet.'"</i></p>	MWRA	FGD with photos, Ch
	<p><i>"Some of the people say, 'lots of organizations come here but no one gives anything.' At that time we try to make them clear. We tell them it is a public awareness programme and it is very useful for us. Some of the people come to us and say it doesn't give anything."</i></p>	MCHW	I, Ch

Sub theme	Evidence	Stakeholder	Method and Place
Dissatisfaction with MIRA and perception that only tangible development is work	<p><i>"I haven't seen anything which MIRA has done".</i></p> <p><i>"They haven't done the work which can be seen by the eyes. They are doing for health, aren't they? They use to walk and ask."</i></p> <p><i>"Gives good suggestions. Ward enumerators are also doing well. They give suggestions. I have heard that they say, like if you do this then you may have that effect."</i></p>	MWRA	FGD with photos, Ch
Difficulties of working without providing tangible benefit	<p><i>"They also say that it doesn't give anything. Like what does MIRA give? They say that MIRA only teaches them. They say that apart from this MIRA doesn't do anything. They say that if the support is provided then our group members would have increased. As the support hasn't been provided the members have decreased from before. They say that the other organizations have support and in their groups there are more members."</i></p>	VDCf	I, Bh
Irritated by questions and lack of service	<p><i>"Some women may feel shy and some may be irritated as they need to answer lots of questions.</i></p> <p><i>"Some of the women say, 'They ask in front of other people and I feel shy so I don't say anything and we don't get anything. (Laugh for a while.) They come to ask us, but neither do they give anything nor we get anything"</i></p>	HV	FGD no photos, Bh

Sub theme	Evidence	Stakeholder	Method and Place
	<p><i>“women say they (MIRA) don’t even give medicine for headache, they just come and ask”.</i></p> <p><i>“The sisters of village say, 'they just come to ask a question, they don't do any work.' Actually, MIRA hasn’t done work. The village sisters say like that. There are still women who have hidden themselves while MIRA staff go to ask”.</i></p>	MWRA	FGD with photos, Ch
	<p><i>“They haven't given us medicine yet.”</i></p> <p><b><i>How do you feel, while they come and ask to you?</i></b></p> <p><i>“They come here and ask us and go. (Smile for a while.) What to say?”</i></p> <p><i>“We send them away saying ‘its good’. They ask whether we are fine or not and we tell them we are fine because they don’t give us medicines. We have taken depo (provera – contraceptive injection). We don’t know whether it is good for us to take depo or not. I always become sick.”</i></p>	MWRA	FGD with photos, Bh
Improvement not dissatisfaction	<p><i>“While taking injection some woman have menstruation and some women don’t have menstruation. Some may have excess bleeding. It would be good if it gives lesson about this and gives medicine”</i></p>	MWRA	FGD with photos, Bh
	<p><i>“if you take your programme over there then it may reach to each and every house as the staff of MIRA go to each and every house”</i></p>	MWRA	FGD with photos, Ch
	<p><i>“To support us it should conduct the training for traditional birth attendant. Like, if it can give technical knowledge to the ward enumerator, it would be good because by this the ward people get the facilities from them”</i></p>	MCHW	I, Ch

(WG, women’s group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)

## Trust

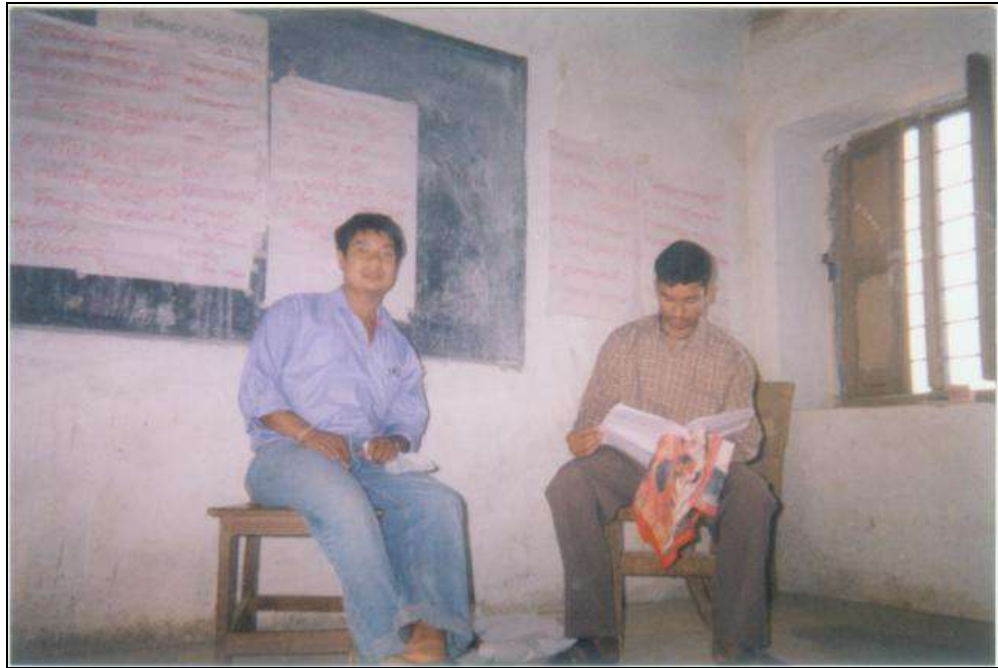
**Figure 31 A woman receiving treatment at a medicine shop (private facility)**

Photograph taken by a women's group member



**Figure 32 A community meeting**

Photograph taken by a man participating in the study



## 7.5 Trust

All respondents talked about aspects of trust and mistrust. There was an expressed lack of trust of health services (personnel, equipment and medication), and some mistrust of non-governmental organisations. Further evidence for this theme is presented in tables 16 and 17.

### 7.5.1 *Mistrust of health services*

#### 7.5.1.1 *Medicine and misappropriation of funds*

All stakeholder groups in both places expressed their dissatisfaction with the health services, particularly the local health services (health post, sub health post and services from female community health volunteers or traditional birth attendants). Respondents tended not to trust the quality of the medicine they received from local providers, believing it to be ‘stale’ or ‘date expired’: *“the date expired medicines are provided which make the patient more sick”* (MWRA, FGD with photos, Ch); or to be a generic medicine not specific to their health needs or age: *“I think doctors give medicine by guessing”* (M, FGD with photos, Ch). Some respondents also suspected health personnel of misusing financial resources, or the registration fee; *“They say that the amount is collected in the fund for buying the medicine. Actually we don’t know about the facts”* (VDCf, I, Bh)

#### 7.5.1.2 *Skilled personnel*

There were complaints about the lack of skilled personnel, and in both places the doctor or ‘in-charge’ was only occasionally on duty: *“It is just for name ‘health post’”* *“Sometimes the doctor doesn’t stay there. The doctor comes once a week...”* (WG, FGD with photos,

Bh) There was some mistrust of the knowledge and practical skills of the health personnel, but respondents also felt that they had not been given the training or capacity to provide better services: *“Many patients come to the health post but there is no in-charge (doctor). Everyone complains about that. The MCHW tells whatever she knows, but she can’t say what she doesn’t know...she can’t provide all the facilities”* (VDCf, I, Bh).

#### 7.5.1.3 Futility of using services

The low quality medicine, lack of medicine, and lack of skilled personnel were disincentives to use the local services: they were perceived to be *“useless”* (MWRA, FGD with photos, Ch), and either referred patients or gave medicine which would not cure the ailment: *“After going (to the health post) they see this side and that side, and they tell to go to such-and-such a place, that is their work” “Sometimes they say that the medicines have finished...that they don’t have. It is better to go directly (to district centre).”* (M, FGD with photos, Bh). The futility of attending the health post was emphasised by respondents that found they had to visit the medicine shop to obtain medicine and respondents felt it was not often worth the 5 rupees that was charged for consultation. There was a perception that consultation was useless without effective medicine: *“if we take the patient in the health post and if they say they don’t have medicine of that disease then we need to bring back without doing anything.”* (WG, FGD with photos, Bh). The health post was only perceived to be effective for ‘normal’ illnesses such as fever, headache and diarrhoea.

Some respondents had had a positive experience at the health post: *“My son had a cough for one month. I took him to health post for check up. He was checked there two times, and she wrote the name of the medicine and I bought the medicine paying 17 rupees, and*



*fed to my son. After that he was cured”* (MWRA, FGD with photos, Bh). Despite this, the lack of trust, in health services came through more strongly in the data. This was also confirmed in the feedback sessions, and even local service providers agreed with this perception (see feedback section). Respondents had a clear preference for traditional healers, private practitioners, and medicine shops where they felt there was more likelihood of their illness being cured: *“though we need to give five rupees, they just give tablets. We have taken them, but they don’t cure, so if we have money we go to the medical, we go to Hetauda (district centre)”* (MWRA, FGD with photos, Bh).

#### 7.5.1.4 Attitudes of health workers

There were concerns about health worker attitudes towards patients. Stakeholders believed that health workers have different attitudes towards different ‘types’ of people. Those who were trained, educated, respected, or known, were likely to get better treatment than others: *“If you are a relative (of the health personnel) then they give the right medicine, otherwise they give brucet (type of pain killer)”* (M, FGD with photos, Ch). In contrast to this, there were also a few instances of particularly good treatment from individual ‘loving’ or ‘polite’ service providers: *“They behave well. (MCHW) is very good, she speaks well and she also provides medicine”* (MWRA, FGD with photos, Bh). Some respondents expressed more satisfaction and trust in services from particular practitioners in medicine shops; *“everyone says take to the medical (shop) of Naak Chuche, he can cure. He is a very good doctor of children...he doesn’t take a check up charge. He gives medicine which cures children immediately...he gives very good medicine”* (MWRA, FGD with photos, Bh).

#### 7.5.1.5 Dissatisfaction among health workers

Morale appeared to be quite low among health personnel and volunteers. Volunteers felt disappointed that they were not called to attend deliveries and were unappreciated at the deliveries they did attend: *“Some of them said, ‘you should give her at least 200 or 100 rupees’, but no (shaking head), they didn’t give me a cup of tea”* (HV, FGD no photos, Bh). The evidence suggests that lack of trust in their abilities is only one of several reasons that health volunteers were not called to attend deliveries. Health volunteers were also unhappy about the lack of appreciation by the ‘doctor’ (or government system) that did not pay them for their work: *“And he said ‘you haven’t done any work’, and I told him: ‘we need money according to work’”* (HV, FGD no photos, Bh). Health workers were aware of the community dissatisfaction and distrust of their services and expressed a sense of powerlessness to do anything about this. Health personnel were also aware that poverty often prevents patients from seeking health services, and they were unable to address this issue: *“I can’t tell them to take her to the hospital as it takes lots of money. If I go there I have to give her medicine and at that time I feel uneasy to ask for money for the medicine”* (MCHW, I, Ch)

**Table 16 Mistrust of health services**

Sub theme	Evidence	Stakeholder	Method and place
Suspicion of misappropriation of resources	<i>“If the doctor writes the medicine for 3 days then the person who is there to give medicine, gives the medicine for 2 days. They have the medicine of that one day by themselves. If (the illness) is cured, then fine. Otherwise, if we go there again then they say ‘we cannot make you well, go to the hospital’. Then we need to go to hospital anyway.”</i>	M	FGD with photos, Ch
	<i>“If I take money, maybe they think ‘that sister of the health post takes money’. I feel so uneasy about this condition”</i>	MCHW	I, Ch
Futility of using services	<i>“the people of the inner village trust him (private practitioner) a lot.”</i> <i>“people used to say it is better to go to the medical (private practitioner) instead of going to that place (health post)”</i>	MWRA	FGD with photos, Ch
Lack of skilled personnel	<i>“Even in the health post there is no good doctor...”</i> <i>“Mostly the doctor doesn’t stay there and peon looks after”</i> <i>“He gives the medicine of headache to the patient of stomach ache. We wish this type of negligence did not happen”</i>	MWRA	FGD with photos, Ch

Sub theme	Evidence	Stakeholder	Method and Place
Lack of skilled personnel	<p><i>"They (villager) might not believe*."</i></p> <p><i>"The villager might be thinking, 'she (health volunteer) can't know anything, can't do anything, she is like us'. But we have taken training in many places."</i></p> <p>*'to believe' and 'to trust' are the same verb in Nepali language therefore the translation may be inaccurate</p>	HV	FGD no photos, Bh
Attitudes of health workers	<p><i>"Although they (women) know the hospital, they say, 'you have taken training there and you know all the sisters over there that's why if you tell them they will do the work immediately. But if we go there, no one knows us so they ignore us'. That's why they (women) ask us to go (with them) so we need to take them to hospital and tell"</i></p> <p><i>"if they behave (badly) with me how do they behave with the other sisters of this village? I am a person who works in the organisation and can understand things, and can speak, if they treated me like that then how do they behave with my sisters who cannot speak?"</i></p>	<p>HV</p> <p>CL</p>	<p>FGD no photos, Bh</p> <p>I, Ch</p>
Dissatisfaction among health workers	<i>"I need to go and give them (medicine), as they don't come. What to do? We refer them to go there ...but they don't come."</i>	VHW	I, Bh

(WG, women's group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)

### 7.5.2 Trust in NGOs

#### 7.5.2.1 Trust of MIRA

We asked respondents about their feelings towards MIRA, and there was a generally positive response. Stakeholders were impressed that MIRA employees visited them often and appeared concerned about their health (weighing babies, asking about their menstruation, and general health of mothers and newborn babies). There were indications that MIRA employee's presence and regular contact with local persons demonstrated their commitment to villagers; *"I think it is good. I think (MIRA) actually has done the work"* (MIL, FGD no photos, Bh). This commitment, trust and presence led villagers to seek advice, care and medicine from MIRA employees. This may help to explain and qualify the data expecting MIRA to provide more tangible support to villagers. Group members trusted the health advice and knowledge that facilitators and supervisors gave them; *"Laxmi madam (supervisor) has told us 'if your children have any problem then if you take to health post then you can get medicine' ...Truly, I took my baby there a few days ago"* (WG, FGD with photos, Ch).

There is also some evidence that villagers felt positive about MIRA's employment of local persons, and employment practices that supported local women, but these data were not well triangulated; *"What MIRA has done is, the women who are educated normally (ie not educated to a high level) are given jobs. Someone's husband might not care for them and (MIRA) provides them with support. MIRA has created a base for them to live...They may have hope"* (MWRA, FGD with photos, Ch).

#### 7.5.2.2 Co-ordination with local health workers

Local health workers trusted MIRA employees, had good relations with them and praised their behaviour; *“(Laugh) I feel happiness and pleasure. I don’t know why, maybe we have the same goal and work, I feel that the behaviour of all the employees is good.”* (MCHW, I, Ch). MIRA employees often offered practical support to health workers, and health workers felt that MIRA complemented their work, encouraging the use of services; *“we meet them (MIRA employees). They come to the mothers’ group meeting. They help on antenatal check up and immunization days.”* (HV, FGD no photos, Bh).

#### 7.5.2.3 Mistrust of MIRA

Although stakeholders were dissatisfied with the lack of tangible rewards from MIRA, this was not expressed through lack of trust. Mistrust of MIRA employees was only reported through suspicions about some ward enumerators not doing their jobs as diligently as they should; *“they should do observation from time to time by going to the village, I don’t know whether they are doing that or not. I think they are doing the observation whether the report is good or not...I ask them ‘do you make your report by walking in the village or you make the report by yourself?’”* (CL, I, Ch). There is stronger evidence expressing satisfaction and trust in MIRA than the evidence of dissatisfaction or mistrust of MIRA; *“I heard one or 2 people say bad things about MIRA among 200 or 300 people which is normal”* (MCHW, I, Ch). This was also validated through the feedback sessions.

#### 7.5.2.4 Mistrust of non governmental organisations

Although respondents mainly expressed trust in MIRA, they also had had some bad experience with NGOs. There was more evidence of mistrust of non governmental

organisations from respondents in one area (Ch) compared to the other. A few respondents felt that non governmental organisations do not always work in a transparent way. This leads to suspicions that the money for projects is taken by corrupt workers or managers; *“It (NGO) just comes, claps, and the budget is gone”* (M, FGD with photos, Ch). Some respondents expressed the opinion that non governmental organisations (including MIRA) from outside the village do not coordinate with existing structures or seek permission to work, and there is a need to work in a sustainable way; *“new organisations should take our advice before they enter the village...why register another organisation?... It is ok that the organisation comes from outside... (but) if it doesn’t get (money) tomorrow then it may move from here...but the (village) organisation exists until the village exists”* (CL, I, Ch)

**Table 17 Trust in NGOs**

Sub theme	Evidence	Stakeholder	Method and place
Trust in MIRA employees	<i>“(WE) asks all about that and takes the report. She asks all over the village. She takes the report of ward number 7 and after taking the report she brings back the medicines for the disease from which they are suffering. Sometimes she tells (you to) go with her”</i>	MIL	FGD no photos, Bh
	<i>“Once my breast was engorged, if Praticha (facilitator) didn’t come at that time my breast would be abscessed. She told me lots of things so I went to Hetauda by taking out the money from group. It was cured after treatment”</i>	WG	FGD with photos Bh
	<i>“There are other organisations too, they are not doing like MIRA is doing here...I tell to other organisations about MIRA and give the example of MIRA. I tell them ‘you also have to do work like MIRA is doing’”</i>	MCHW	I, Ch
Co-ordination with health services	<b><i>How do you feel when you meet them?</i></b> <i>“I feel pleasure. There is two-way communication. Also communication about the work which has been finished, and (the work) which is left. It’s good”</i>	VHW	I, Ch
	<i>“Mostly we talk about sharing help...they treat me well and although they are (more) senior than me in terms of education and work...some people have a proud feeling that they are senior staff, but they (MIRA employees) don’t have like that type of feeling”</i>	VHW	I, Bh
Mistrust of MIRA employees	<i>“They (WE) come once in 2 or 3 months”. “She comes sometimes. Mostly she doesn’t come.” “Sometimes she comes every month.”</i>	MWRA	FGD with photos, Bh



Sub theme	Evidence	Stakeholder	Method and Place
Mistrust of NGOs	<i>“Every organisation is same. Every organisation comes and becomes fat by themselves.”</i>	CL	I, Bh
	<i>"Sisters use to say, 'why to go to the health post, PLAN has built the building by spending lots of money, (but) doesn't keep a skilled doctor there"</i>	CL	I, Ch
	<i>“The money comes in the VDC”</i>	WG	FGD with photos, Ch
	<i>“Nothing will happen here”</i>		
	<i>“And they (non governmental organisations) do the small work and they show the money is spent on that and then they finish”</i>		
(WG, women’s group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)			

## Pluralism

**Figure 33 Shaman (*dhami jhankri*) performing a healing ceremony for a child.**

Photograph taken by women's group member. He has a drum to summon spirits, a cockerel to sacrifice as an offering, ashes, leaf plates, water and incense.

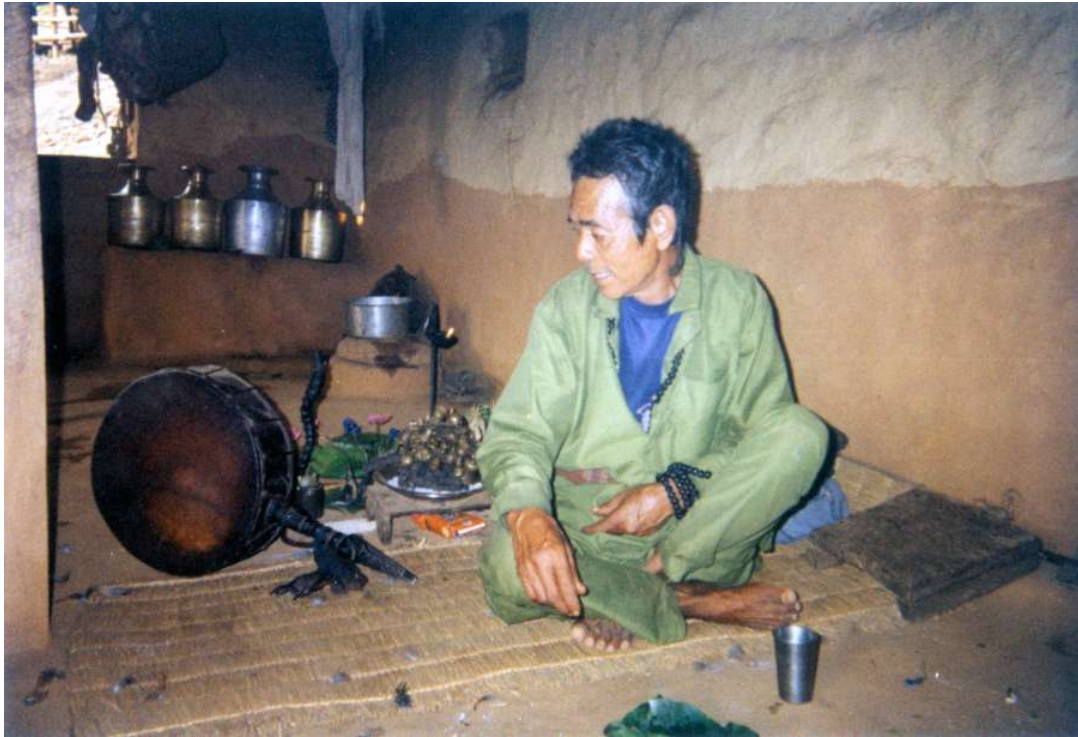


## **7.6 Pluralism**

All stakeholder groups talked about their own, and other villagers' plural beliefs in allopathic medicine and in healing by shamans (shamans are called *dhami jhankri* in this area). Calling on shamans to perform healing ceremonies is a common practice in the study area. When respondents were given cameras, they often took photographs of healing ceremonies, despite the short period of time that they had their cameras (Figure 33, 34, 35, 36). Additional evidence is provided in table 18.

**Figure 34 A shaman with his drum**

Photograph taken by a married woman of reproductive age who participated in the study



**Figure 35 A Christian healing ritual**

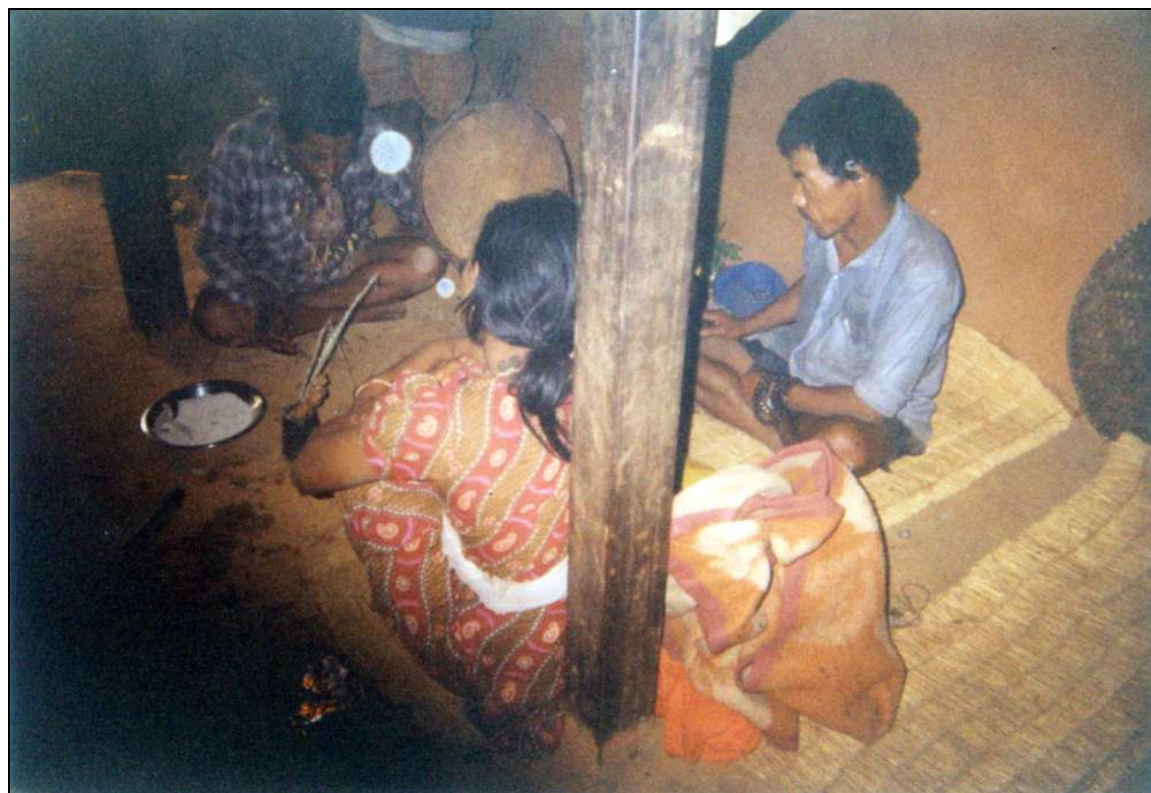
Photograph taken by a man participating in the study





**Figure 36 A shaman performing an exorcism**

Photograph taken by a women's group member



### **7.6.1 Identification and treatment of cause of illness**

Health personnel and women's group facilitators talked less about pluralism than other respondents. This could be due to the fact that they felt they should not express plurality of belief because of the nature of their employment, or that they actually do not have plurality of belief. Generally, respondents felt that unwell persons could only be cured by identifying, and then treating the cause of the illness. If a spirit or god caused the illness, it was not sufficient to visit a medicine shop or the health services, and the services of a shaman should be sought to identify and satisfy the spirit, thereby curing the patient: ***"How do you identify that the child is possessed by Nepali?"*** *"The shaman can identify" (All speak at once)* (WG, FGD with photos, Ch). If the patient is possessed, the type of treatment is dependent on which spirit or god has affected the patient: *"He asks for duck eggs, and also hen (eggs). According to whatever has possessed (the patient) he demands the things"* (M, FGD with photos, Ch).

Often, respondents distinguished between symptoms that were caused by a ghost, spirit or god, and other symptoms that required medical intervention: *"We show (the shaman) if the problem is heart disease, or sudden pain in the wrist or if you are possessed by a ghost. We should go to the medical if we are influenced by another disease"* (M, FGD with photos, Bh). These symptoms were not uniform across respondents or places. Respondents sometimes used their classification of symptoms to guide their choice of treatment, or they would call a healer regardless of symptoms. It is not clear from the data whether a healer should be sought 'just in case' the illness was caused by a spiritual force, or if the spirit would be angered if medical treatment was sought without spiritual mediation (with

adverse consequences to the patient). It was also possible that a shaman should be called to control the interaction between the spiritual force and the allopathic medicine so that the patient could be cured: *“The medicine won't work if (the patient) is possessed by anything. So you shouldn't take (to hospital) before you exorcise.”* (MWRA, FGD with photos, Ch).

### **7.6.2 Traditional to plural**

Villagers who do not ‘understand’, or have traditional beliefs, tend to depend only on shamans when they have a health problem: *“those who understand, they go for a check up, but those who don't understand, they don't go for check up”* (HV, FGD no photos, Bh). There is an awareness that it is not modern to believe in the power of shamans and ghosts, and villagers acknowledge their difference and superstitious-ness; *“most people get well using shaman, although it is said there is no shaman, it is superstition, scientist says there is no shaman and no witch. Maybe they haven't seen a ghost and that's why they say so.”* (M, FGD with photos, Ch). They defend their beliefs by telling stories of their successful encounters with shamans and their experience of ghosts in the locality: *“people say there is no (witchcraft) but I believe in that. I was not cured by the hospital. I became more severe by going to hospital”* (CL, interview, Ch). According to respondents, the numbers of people that only depend on shamans to treat their illnesses are reducing: *“now people believe less then before”* (F, I, Ch). In recent times, there has been a change to plural belief, whereby care is being sought from both shamans and health services or medicine shops. *“Now, people think that we need to show both to the shaman as well as take to the hospital”* (F, I, Bh). These changes are attributed to the increase in non governmental organisations, shamans receiving training from the health post, the inability of shamans to cure modern illnesses, and increasing diversity of opinions: *“People used to show the*



*shaman before for the sick children but now the shaman cannot cure...before there were only the ghost of Nepal and the shaman could cure that...if the patient get sick by other diseases, then how can they cure?” (HV, I, Ch). Despite this change to pluralism of belief, the services of a local shaman were usually sought first: “(the evil spirit) should be removed first, then after (you) should go to the hospital” (CL, I, Bh). In the simplest ceremony, the shaman tested the pulse of the ill person, chanted a mantra, threw uncooked rice and waved incense sticks in the air: “first he catches the pulse. Then he says ‘(the patient is) influenced by such and such and you do...(interruption)...First he throws the uncooked rice and if (the patient is) not recovered then he does mediation.” (M, FGD with photos, Bh).*

### **7.6.3 Accessibility**

Previous studies that specifically examined care seeking in the perinatal period found that the shaman called to administer the initial exorcism or blessing was often a family member, or neighbour (Tamang et al., 2001). There was also some evidence of this from the data: *“She was sick at that time. He is throwing uncooked rice at the time I took this photo (pointing to the photo). He is the shaman and she is the daughter.” (WG, FGD with photos, Ch)* Although data was not gathered specifically on cost of services, this type of initial exorcism appears relatively low cost or free of charge, using available materials of incense sticks and uncooked rice *“in the market people ask for money, in the village they exorcise without payment” (WG FGD with photos, Bh).* After completing this ceremony, families feel more comfortable purchasing medicine or using the health services. The perceived severity of the illness and the amount of money available in the household appear to be the main deciding factors of the type of action to be taken next: *“we take to the hospital. The*

*village people also do the same thing...those who have money they take*” (HV, FGD no photos, Bh). Respondents felt that if a family was poor they were more likely to observe the patient, waiting for a longer period of time after initial exorcism, before seeking the services of a more ‘senior’ shaman or calling the same shaman to perform a more powerful ceremony. This type of shaman could be more specialised or more reputable, and able to perform more powerful ceremonies: *“if we showed to the shaman then we need to show lots of shaman”* (HV, FGD no photos, Bh) (Tamang et al., 2001). Most respondents in this study said they usually watch and wait for a while, and then seek health services if their initial interaction with a shaman was unsuccessful: *“We watch for the whole day, if it is not cured after tomorrow then we go to the hospital.”* (MWRA, FGD with photos, Bh).

#### **7.6.4 Expected service and payment**

Respondents tended to know what to expect from shamans and therefore have an idea of the expenses likely to be incurred, which contrasted with the unknown expense of the medicine shop or hospital. Payment of money or payment in kind was given to the shaman for their work: *“some give money while some give grains.”* (MIL, FGD no photos, Bh), and therefore villagers are more likely to have payment for shamans around their homes. If care at a hospital or medicine shop is sought, money is usually borrowed from different friends and neighbours: *“those who don’t have, they collect donations”* (HV, FGD no photos, Bh). If, on arrival at the hospital, the expenses are too much for the family to afford, it is even more difficult to find a loan where there are few friends and family to help. Shaman’s go to the house of the sick person, which prevents the family from paying to travel to a health facility, or paying others to carry a sick person to a health facility: *“the*

*man who carried was given 100 rupees”* (CL, I, Bh). The feedback data also supports this link with socioeconomic status and dependence on shamans.

#### **7.6.5 Value for money**

Related to this issue was concern about ‘getting something for your money’ or value for money. At the health post there was a nominal charge (five rupees – around three pence) for a consultation, and depending on the availability of medicine or type of treatment needed, there was a chance that nothing will be given in return for these five rupees apart from referral advice. The medicines received were sometimes not a full course, and patients tended not to trust the quality of consultation or medicine (see Trust theme).

Although there was a certain amount of scepticism around the work of shamans, there was a feeling among respondents that at least you were receiving *something* by calling a shaman.

#### **7.6.6 Scepticism**

There was a certain amount of scepticism about the work of shamans. Respondents had experienced success and failure with both doctors and shamans - and their tools (medicine, drum/sacrifice/uncooked rice etc) - and therefore have few reasons to trust one more than the other. Respondents accused shamans of promoting their work to make a living: *“this is a way of (finding food to) eat by shamans”* (HV, FGD no photos, Bh). Whilst talking about shamans or their ceremonies, there was usually laughter or uneasiness, and this may come from their feelings of scepticism or from their embarrassment at holding ‘old fashioned’ views. There was more debate and discussion of extent of belief in shamans in

interviews with community leaders and in the focus group with female community health volunteers.

#### ***7.6.7 Pluralism in Christian population***

In several of the focus groups there were Christians present. Christians make up a very small proportion of the study area population, and they were probably captured because areas relatively close to the district centre of Hetauda were sampled. Christianity is spreading in Hetauda and different respondents reported several Christian missions. From the data that we collected (which was by no means a study on shamanism or Christianity) it appears that Christians also perform some kind of healing ceremony including blessing and prayer, and tend to wait for this to take effect before proceeding to the hospital or medicine shop: *“they had arranged a camp at the health post. When the patient came then they prayed to god first, then they were sent for a check up”* (HW, I, Bh). Respondents also mentioned other forms of healing, and although these were much less widely used, respondents were open to exploring spiritual healing generally. The belief that a spiritual imbalance of some kind (curse, spirit possession, god punishing for wrong doing, or a bodily imbalance of heat and cold) can cause illness was strong among the study population.

**Table 18 Pluralism**

Sub theme	Evidence	Stakeholder	Method and place
Identification and treatment of cause of illness	<i>“Medical treatment should be done. If (a person) is possessed by something then it would be removed after exorcising because I believe in both shaman and medical. I too...at first I show the shaman and then I take to the medical”</i>	MWRA	FGD with photos, Ch
	<i>“After exorcising then (we) take the patient to the hospital...It is not good to go to medical treatment immediately.”</i>	MIL	FGD no photos, Bh
	<i>“I heard that they (villagers) think they should exorcise first because without exorcising, the medicine cannot work. While I was giving medicine people said they should show the shaman first then have medicine.”</i>	HW	I, Bh
Traditional to plural	<i>“people used to depend on the shaman before, but now they don’t...they don’t stay doing exorcism only, anyway they take (to hospital)”</i>	CL	I, Ch
	<i>“At first we show to the shaman” (other respondents also agree) “If we take sick people to the hospital at once and if he or she is possessed by a ghost then the patient will not be cured.” “At first we exorcise (manchhanu) by the shaman than we take to the hospital”</i>	WG	FGD with photos, Ch

Sub theme	Evidence	Stakeholder	Method and Place
Traditional to plural	<i>“The patient is shown to the shaman for treatment and if they do not recover from the shaman’s treatment, then they are taken down to the medical.”</i>	M	FGD with photos, Bh
Accessibility	<i>“Here there are lots of shamans”</i> <i>“Most of the people from here throw uncooked rice and wave incense sticks”</i> <i>“Her husband also throws rice”</i>	WG	FGD with photos Bh
Value for money	<i>“First of all for all diseases we show to the shaman”</i> <i>“This system has been carried from the grandfather's time. It is said that the money is misspent if we take to the medical.”</i>	WG	FGD with photos, Bh
Scepticism	<i>“He might have offered uncooked rice, chicken, money, home made liquor (laughing)”</i> <i>“The old man needs home made liquor (laughing)”</i> <i>“He says he cannot work unless he is drunk”</i> <i>“That is the shaman’s work, they need a big chicken”</i>	M	FGD with photos, Bh

Sub theme	Evidence	Stakeholder	Method and Place
Scepticism	<p><i>“He was possessed by the ghost (Seems that she is joking.) (All the participants laugh.) If we show the shaman then he says they are possessed by a ghost.”</i></p> <p><i>“Exactly, if we show to the doctor then he says we are caught by disease and if we show to the shaman then he says you are possessed by a ghost.”</i></p>	WG	FGD with photos, Bh
Christian healing as similar to healing by shamans	<p><i>“ (we) just pray by sitting in front of the sick person...through prayer the patient becomes well...if the disease is not cured by prayer then we take to the hospital immediately.”</i></p> <p><i>“On the 9<sup>th</sup> day my baby became so thin. Because he was possessed by Sukuwa (ghost)...we showed to lots of shaman but they couldn't cure. I took the baby to the health post and they suggested to feed him ORS...then after that I took him to church...they did a prayer...we prayed in the church and by doing that he became cured.”</i></p>	MIL  MWRA	FGD no photos, Ch FGD with photos, Ch

(WG, women's group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)

## Barriers to care

**Figure 37** An unwell woman being taken to the District hospital in a bamboo basket (*dokho*)

Photograph taken by a man participating in the study





## 7.7 Barriers to care

In all methods of data collection there was evidence of the many obstacles preventing villagers from receiving health care in a health facility. Some of these barriers were discussed in detail in the thematic sections of trust, plurality and learning and development, such as: lack of trust in health services, and low morale of health workers; the lack of involvement of men in maternal and newborn care; and the extent of the population that is traditional and has not been exposed to different opinions. There were many issues that did not fit into these thematic categories, and therefore they are discussed in the theme: barriers to care. These barriers include: *laaj* (shame or embarrassment), problems of lack of demand for services and difficulties of supply, and the accessibility of services. Further evidence is presented in table 19.

### 7.7.1 *Laaj - shame or embarrassment*

*Laaj* was discussed as a reason for non disclosure of information, and a reason for not seeking health care during pregnancy or birth: *“Sisters of this village don’t say anything about the pregnancy because they feel shy. They carry heavy loads and bleeding occurs. They stay without saying to anybody”* (F, I, Bh). Discussing health issues with men, and being ‘too old’ or ‘too young’ for pregnancy also induced *laaj*: *“they say ‘we feel shy and scared’”* (MWRA, FGD with photos, Ch). Women reported their friends or themselves to be embarrassed telling male MIRA employees about their menstrual status or their health problems: *“(feeling embarrassed) He came to my house and asked me whether I had any problem and I said no...He was alone, and I too was alone and I thought, ‘how can I tell*

*him about this''* (WG, FGD with photos, Ch); and men are embarrassed to hear about what women learn in women's group meeting; *"they don't tell at home what they came to know (at the meeting)...even we don't ask them what they have done"* (M, FGD with photos, Ch).

### **7.7.2 Problems of lack of demand for services and difficulties of supply**

Some respondents discussed the difficulties of trying to help families who ask for help at the last moment, or do not ask for help at all: *"one woman gave birth at 12 o'clock in the night but the placenta hadn't been delivered. I didn't know. They didn't come to call (me)"* (HV, FGD no photos, Bh). There was also some data complaining that health volunteers did not come when they were called: *"she didn't come while Motkan's daughter in law was going to give birth"* (WG, FGD with photos, Ch).

Volunteers and health workers discussed the difficulties of providing services. Patients tended to have high expectations, and volunteers sometimes begrudged the duty to carry out many responsibilities at their own expense: *"I need to take the pregnant woman to the hospital...need to contact the nurses, don't I feel hungry?"* (FCHV, I, Ch). Health volunteers particularly found it difficult to be 'on call' 24 hours and volunteers were busy with other work that they needed to meet their living expenses. One volunteer was elderly, and tended not to come when called because she found it difficult to see at night, and did not like to attend to the dirty, and polluting business of childbirth: *"I feel lazy sometimes and don't like to go...who likes the dirty things? Do you like that?"* (HV, I, Ch). The theme of trust also demonstrated that health workers and volunteers feel their workload is not equal to their remuneration.

This theme area is closely related to the data on pluralism of belief and lack of trust in local services. Lack of demand for health services is partly explained by issues of cost, pluralism of belief, and lack of trust in local health services and the medicine provided there. This would suggest that there are problems of demand for health services, as well as of supply of health services in the study area.

### **7.7.3 Accessibility of services - Money**

Respondents discussed the lack of locally available health services and they were concerned about costs they were likely to incur reaching and receiving services: *Can you tell me the reasons why you didn't go (to the district hospital?) "Maybe I thought that it takes lots of expenses"* (WG, FGD with photos, Bh). Money was a barrier to care seeking mentioned by all respondents: *"without money can we check-up? Do they check up without charge?"* (MIL, FGD no photos, Bh). The data suggests that health care providers and medicine shop owners sometimes give treatment and medicine on credit to poorer persons, and have difficulty recovering this money: *"he (medicine shop owner) gives medicine in credit to those who don't have money"* (CL, I, Ch). Resources that villagers can access for their health care needs are scarce, and donations are usually sought from friends, neighbours and money lenders: *"a pregnant woman came here for delivery but we couldn't conduct the delivery. She didn't have money, it was around 8 or 9 o'clock in the evening. The people of this community collected money. Everyone paid 10 or 20 rupees and sent her to the district hospital"* (VHW, I, Bh). MIRA fund was considered beneficial because it saved time in emergency situations, and the money was locally available: *"If the money is kept in the fund, the money is available immediately when it is needed. We don't need to ask other (people)."* (M, FGD with photos, Bh). The availability of the fund enabled families to take decisions independently, and they did not have to rely on others which is

also a positive aspect of the funds: *“by bowing down...we need to take a gift to the zamindar’s (landlord’s) house...instead of doing that if we save money in the fund then we can take out whenever we need”* (WG, FGD with photos, Bh). These findings are also triangulated by my research specifically on fund management and utilisation (Morrison et al., 2008b)

#### **7.7.4 Accessibility of services – distance**

Many respondents talked about their lack of proximity to a road or public transport impeding their access to services: *“there are problems of transport in Bhorle, and because of this the people from there who come for a check up say, ‘we will pay money so you keep expensive medicine here too’”* (WG, FGD with photos, Ch). Other respondents talked about the difficulties of managing stretchers or *dokho* (bamboo baskets) on difficult terrain: *“to take to the hospital from here we need to carry on the dokho...otherwise if the patient cannot sit in the dokho then (we take) by wrapping in the bed sheet and making jholungo (cradle)...there is no choice although it is not easy”* (CL, I, Bh). Finding someone to carry the patient was also discussed as a issue in accessing care: *“if the family member becomes sick and they need to take (to hospital) then they need to search for the man to carry, they need to ask for help from the brothers of the village”* (WG, FGD with photos, Bh).

The stretcher strategy developed by the women’s groups (managing existing stretchers, or buying new stretchers) was discussed in one study area (Ch) as a resource enabling transport difficulties to be overcome: *“If there is stretcher then it is easy to carry. How can we take the sutkheri (delivering or postpartum) mother by walking?”* (WG, FGD with photos, Ch). The group and facilitator discussed making more stretchers for places in

different parts of the VDC, to make them conveniently available to more women and villagers: *“we have planned to make another two (stretchers)” “one can be used by the people of the higher cluster of houses (tol) and one for the people of this cluster (tol)”* (WG, FGD with photos, Ch). The other study area is hilly and the group have decided not to manage a stretcher strategy. One respondent from Bh discussed the unsuitability of stretchers for their village: *“the stretcher is not effective in the hilly area”* (CL, I, Bh).

Transport difficulties were also experienced because of national strikes called by the Maoists: *“if (the illness) becomes serious on the time of vehicle strike then by putting on a stretcher the patient can move”* (MWRA, FGD with photos, Ch), and the difficulties of getting transport, or even walking around, at night time because of the army imposed curfew: *“we were scared whether they may shoot if we walk by lighting a fire in the group...(before,) while taking a patient the army killed the patient, we were scared thinking that type of incident may happen to us also”* (CL, I, Bh).

#### **7.7.5 Accessibility of services – Clean Home Delivery Kits**

In one of the study areas, the groups had made Clean Home Delivery Kits (Ch). In the other study area the women’s group had not made kits, but they were produced by another MIRA women’s group in the area, and distributed by health volunteers. The local availability of the clean home delivery kit was discussed as a positive incentive to use: *“they are getting (kits) at their home so they say it’s good” “they say that they don’t need to go and buy in other places, ‘it has become easy for us’.”* (WG, FGD with photos, Ch). Clean home delivery kits were discussed in terms of their cheap cost and the convenience of having everything needed for delivery and care of newborns in one packet: *“Before the thread was*

*cut from many dresses (laughing), no-one ever kept the plastic on the floor...now everything is available in one place. Because it is available people feel good. They feel it is cheap” (F, I, Ch). Respondents also recognise the value of local production because the kits are easy to re-supply, and this can be done independently on decision of the group:*

*“(the Clean Home Delivery Kit) is good. It will be good in the future. They (women) don’t need to ask others. We need to be strong and stand on our own two feet.” (CL, I, Ch).*

Although the local availability was a strong incentive to use the kits, health volunteers in Bh felt that demand for the kits had been created by MIRA women’s groups, and therefore those who wanted a kit would also buy them if they were not locally available: *“Now in the village people come to ask whether we have delivery kits or not.” “They didn’t know before but now they come to ask (for kits) ...some of them go to the market if we don’t have (them).” (HV, FGD no photos, Bh).*

**Table 19 Barriers to care**

Sub theme	Evidence	Respondent	Method and place
<i>Laaj</i> (embarrassment)	<i>“the main problem of women is white discharge, pain in lower abdomen, but normally they don’t tell others about this”</i> <i>“Some of them don’t tell because they feel shy”</i>	WG	FGD with photos, Ch
	<i>“usually women don’t tell their problems to men. This is the custom existing in our village”</i>	CL	I, Bh
	<i>“there is one woman she is poor (and) of old age and also is pregnant. We have tried to bring her to the group and also for antenatal check up but she won’t come. There may be various reasons...one thing is poverty, another is what others might say when she goes for a check up”</i>	F	I, Ch
Problem of lack of demand for services and difficulties of supply	<i>“they come to buy (clean home delivery kit) in my house but they don’t call me at the time of delivery”</i>	WG (respondent is HV)	FGD with photos, Bh
	<i>“if the patient comes then we need to see them while leaving all our work”</i>	HV	FGD no photos, Bh
	<i>“...we need to do whatever we know. If we cannot do then we need to take them in the right place”</i>		
	<i>“if we say; ‘take them there’, then some of them say; ‘we don’t know the place’”</i>		

Sub theme	Evidence	Stakeholder	Method and Place
Problem of lack of demand for services and difficulties of supply	<i>“what I have seen is that the stretcher is only provided when the health post is open”</i>	F	I, Ch
Accessibility - money	<i>“He said, ‘I don’t have money sister, what to do?’ then I gave him 500 rupees to do the work and he returned the money to me after 2 or 3 months”</i>	HV	FGD no photos, Bh
	<i>“...one woman came for delivery, she didn’t have any money at that time. She had brought her goat with her by thinking if she sold the goat she could do medical treatment. She didn’t find anyone to buy her goat, that’s why we gave her money and took her to hospital”</i>	M	FGD with photos, Ch
	<i>“I’ll take them (children) (to the doctor) tomorrow or the day after tomorrow whenever I have money”</i>	MIL	FGD no photos, Bh
MIRA fund beneficial because of accessibility and enabling independent decision making	<i>“if pregnant women have any problems they don’t need to walk to the village to take a loan...they can take out money from the committee”</i>	VHW	I, Bh
	<i>“we can take out money immediately if we need”</i> <i>“if there is a problem then the patient may die while looking for money”</i>	HV	FGD no photos, Bh
Accessibility - distance	<i>“we don’t have any facilities”</i> <i>“...we need to take to Hetauda for treatment. The hospital is far from here. We don’t get whatever we need in the village.”</i>	WG	FGD with photos, Bh



Sub theme	Evidence	Stakeholder	Method and Place
Accessibility - distance	<i>{There is an (army) barrack below...it affects their health if they become sick in the night then they need to stay at home the whole night as it dangerous to come out of the house}</i>	RT notes from WG	FGD with photos, Bh
	<i>“we have bought a stretcher to take women when they are ill. The vehicle comes in its own time. Because of this, a stretcher is very necessary”</i>	HV	I, Ch
	<i>“It is necessary to carry on the stretcher to the tempo stop” “Although the tempo goes to my house it would be easier on a stretcher because the road is not good, it is a stony road”</i>	WG	FGD with photos, Ch
(WG, women’s group; HV, Health Volunteer; MWRA, married women of reproductive age that do not attend the group; MIL, Mother in law; M, Men; MCHW, Maternal Child Health Worker; Bh and Ch are place names; FGD, focus group discussion; I, interview; Obs, observation)			

**Figure 38 A woman and her children washing plates.**

Photograph taken by a women's group member



## 7.8 Results of feedback sessions

This section is a description of the results of the feedback sessions conducted with some respondents. Table 19 is an overview of the consensus outcome of the feedback sessions. Feedback was completed separately with a Village Health Worker (male), a Maternal and Child Health Worker (female), a group of married women of reproductive age and two women's groups. Methods of data collection and analysis are detailed in chapter 6, methods. Respondents largely agreed with the thematic analysis, with the exception of mistrust of NGOs and a few clarifications.

There were several limitations of the feedback that are discussed in Chapter 8. Despite these limitations and difficulties, feedback was useful in exploring the validity of the thematic analysis. Square brackets are used to display data as they are not quotes taken from transcripts, but quotes taken from reports made of tape recordings.

### 7.8.1 Agreement with initial thematic analysis

While discussing the theme of expectations of NGOs, distrust of government was further explored. Community disappointment with MIRA was not emphasised. This is illustrated by the reports of MCHW and of MWRA:

*[MCHW: If the organisation can give visible things, I don't say no! (laughs)...It is good to expect but it is another thing whether the expectation can be met or not.]*

*[MWRA: If MIRA provides only knowledge, then we cannot ask for anything. We cannot get things by asking for them. It is good...the sisters of each ward have got jobs.]*

There was consensus among respondents supporting the thematic analysis of perceptions that groups and NGOs are ways of progressing and learning. There was also agreement with results of the sub theme of the threatening nature of women gaining knowledge and working with NGOs in groups. One women's group member said: *[men don't allow women to go outside the house...they are not allowing women to go outside because if they go outside, then they will learn new things and they will become more clever than men.]* Another women's group member agreed saying: *[they say 'what do you get by going to the group? If you do work then it would be better. You just go there and meet your friends and talk about nonsense matters.' Women become clever by going to groups, and they become leaders].*

The MCHW also felt that there are advantages to involvement in group work: *[no-one gets 100% support for any programme. The matter of group is for public awareness. We need to pay money to learn new things. It is beneficial to the community people as they learn about new things by going to the group without paying money. Those who don't know how to develop knowledge, they just think life is to stay at home and eat.]*

Mistrust of health services was also an area of strong agreement. Respondents told more stories of 'negligence' and the health workers were also aware of and in agreement with the community opinion:

*[RT: Some of the people think that they don't trust the quality of services and the medicine of the health post are not...(interrupted)]*

*VHW: it's true, it's true...it's true that people think they don't get quality services because we are not skilled...every staff member should be skilled and needs to be able to tell the village people.]*

Respondents generally agreed upon the existence of a plural belief system. This enables care to be sought from healers or medicine shops or 'big hospitals' – whichever is closer, cheaper, will provide the best service, and is most likely to cure the problem.

*[VHW: first they show to the shaman and if it becomes severe then they come to the health post. This might happen because the shaman lives nearby their house and also it is about their beliefs. This is what they have been doing from generations before. It is not confirmed that the shaman can cure all diseases. Some of them can cure and some cannot. In spite of this they use medicine after showing to the shaman.]*

Co-operation was not the subject of much discussion but there was unanimous agreement of this being true of their village. Respondents felt that caste and gender discrimination also exist and affect their interactions in the village. The mothers group commented about some of their friends going to a wedding party in a low caste (or untouchable) household:

*[they didn't die even though they ate at her house (laugh).]*

The MCHW talks about the difficulties of gender discrimination: *[About gender discrimination issues, we cannot change at once. We need to work for it and one who is working against it is moving forwards. Though people are literate they are also discriminating between son and daughter... the main hindering factor is family.]*

### ***7.8.2 Disagreement with initial thematic analysis***

The unanimous nature of disagreement to distrust of non governmental organisations is interesting. This may be related to a fear of decrease in access to resources or contributions from MIRA in the future, but it also indicates that although distrust of NGOs was raised in initial data collection, this may not be a common overall impression. This dialogue illustrates:

***[RT: Not each and every NGO. Just one or two and just some of the time (they are not trustworthy)***

***VHW: We shouldn't give priority to this opinion.]***

**Table 20 Consensus outcome of feedback sessions**

Stakeholder	Plurality	Mistrust of health services	Mistrust of NGOs	Some say groups are opportunities for learning	Some say groups are bad, women are lazy, and some feel threatened	Expectation	Co-operation	Caste and Gender discrimination
VHW (Bh)	Agree*	Strongly agree	Strongly disagree	Agree	-	Agree	Agree	Agree but changing
Women's group (Bh)	Agree*	-***	-	Agree	Agree	Weakly agree	Strongly agree	-
MCHW (Ch)	Agree*	Agree	Weakly agree	Agree	Agree	Agree	Agree	Agree**
MWRA (Ch)	Agree* but changing	Strongly agree	Disagree	Agree	Agree	Weakly agree	Agree	Agree but changing
Women's group (Ch)	Strongly agree	Strongly agree	Disagree	Agree	Agree	Agree	-	-

\*They agreed that communities believe in medicine and traditional healing, but also clarified by commenting that distance and cost also influence the use of services and healers.

\*\*She also added the problem of Maoist in the community and the lack of freedom that people have to move around and use services.

\*\*\*blank spaces indicate that the response to the theme was unclear or not discussed.

## 7.9 Results of the second phase of data collection

This section is a description of the data collected in the second phase of data collection in an area that had not received the women's group intervention. The data collected is of a similar thematic nature to the first phase of data collection, and themes that emerged from the data were: learning and developing, context affecting social development, feelings about MIRA, trust, and barriers to care. Due to the limited number of discussions, triangulation was more difficult to examine, therefore a table of supporting quotations has not been provided.

### 7.9.1 Learning and developing

Respondents were positive about non governmental organisations and felt them to be a source of learning and a way forward, a way to enable social development of their area: *"We learn knowledge through you and tell about that in the group."* *"We can work at home, in our free time we can go to the village meeting. We can learn something from there and tell that to others."*

(HV, FGD no photos, Chit). The development of transport systems, increased linkages to Kathmandu and contact with persons who go outside of the village was also acknowledged as a source of development: ***How does change occur in these aspects?*** *"By the means of communication". "We walk outside too"... "We get new knowledge from people who come from Kathmandu"*. (M, FGD with photos, Chit).

Respondents also experienced people who do not 'understand': ***Can you tell me***



*what reason did people leave the group, by what reason they didn't like to stay in the savings group? "They didn't understand." "They followed whatever other people said, and left the group. They don't understand matters." (MWRA, Group int with photos, Chit). Men discussed trying to help and convince those who do not 'understand', but they felt this was less effectual than if a person employed by an NGO came to convince them: "We tell them and they hear and then leave it. But if you come and tell about it then it would be different. We live here and work on the farm and we know about it but if we tell them about it then they feel like 'he is also farmer so how does he know'. If somebody comes from outside, even though he or she is not literate, they believe. It makes an impact." (M, FGD with photos, Chit).*

### **7.9.2 Context affecting social development**

Caste or ethnicity was mentioned as a barrier to social development. Social change through lessening gender discrimination or increasing awareness among women was also discussed: *"It becomes like 'Ek jana le aama mam ek jana le baba mam" (proverb - mother feeds one child and the father feeds one child). The people of our generation were also not educated. Now it becomes very easy. We can get education. We are able to hear good things. Before no one could speak Parbate (Nepali) language, people just talked in Tamang language. Now, it is developed. We can hear good things. We are able to give education to the children."* (MWRA, Group int with photos, Chit).

### 7.9.3 *Feelings about MIRA*

Health volunteers were very positive about what they had learned in the health training and health volunteers, women and men also felt that the WE was having a positive impact on health in the area: *And how do you feel while they come to ask? "I feel good." What is good? By what reason you feel good? "She had said it is for our health"* (MWRA, Group int with photos, Chit). Men were happy about the work of the WE because they felt they were increasing awareness of health problems, and offering advice to women: How do you feel while they come to ask? *"We feel happy"*. By what reason do you feel happy? *"Our mother, daughter in law and wife don't know about it. Definitely those who come to ask may tell something to our family, though they don't tell us. Or if somebody has already given birth to 3 children then she would be asked not to give birth to another baby. If man is aware then it's not necessary but if men are not aware then by their effort women become aware. That's why we are satisfied."* Men were hopeful that MIRA would bring a more substantial programme: *"If MIRA works here in future and teaches us about health then our habits would develop."* (M, Group int with photos, Chit).

### 7.9.4 *Trust*

Issues of trust were also similar to first phase data, with mistrust of non-governmental organisations mentioned (although to a lesser extent than praise of non governmental organisations), and lack of trust in the local health services and the medicine available: *"There is no good medicine in the health institution"* (MWRA, Group int with photos Chit). There was lack of trust in the expertise of health post staff, and complaints about lack of medicine: *"Only the (maternal child health worker) is there."*

*Actually, she only has experience. She has no education. She hasn't passed her SLC (secondary education qualification). People like that are working in the health post, so how can we get good health services. If it is health post then it should do normal treatment. It doesn't have any (para)cetamol for fever. If someone has stomach ache then there is no Amjit (medicine). There is no Jeevanjal (oral rehydration solution). It is health post only in name. Actually, the public over here have not got services from the health post.” (M, FGD with photos, Chit). Health volunteers found it difficult to motivate villagers to go to the local health facilities because of the lack of facilities there: “We send to health post and if they don't get medicine here then come back and scold us: ‘I went to the health post as you told me, but we have come back with empty hands’.” (HV, FGD no photos, Chit)*

#### **7.9.5 Barriers to care**

Barriers to care were included lack of awareness, distance, transportation, poverty and also the lack of adequate local health care: “Those who understand go and ask to take to the hospital. If the people who cannot take to the hospital for those we arrange loan. The main thing is shaman, then afterwards, hospital.” (M, FGD with photos, Chit). Plural belief in shaman and in allopathic medicine was also common in this area with signs of some social change towards pluralism of belief and care seeking: “families call those shaman in whom they have faith. We (Pointing to other men), we go to there and say that you shouldn't show to the shaman only. We also scold the shaman: ‘you should take responsibility if you can save or not, otherwise if something happens then you will be in trouble.’ Then after that the shaman is also scared. Now, people are not dying by only keeping on believing in shaman.” (M, FGD with photos, Chit).

**Figure 39 A community planning meeting**

Photograph taken by author.



## **8 Discussion**

The efficacy of a women's group intervention to improve maternal and newborn health was tested in rural Nepal using a randomised controlled trial design. Results of the trial showed significant reduction in neonatal mortality and increased care seeking behaviour in intervention areas as compared with control areas. The objective of this thesis was to explore how communities experienced the women's group intervention and explore what factors might have affected its receipt and the community response. This study explored the context of the intervention to enable inferences to be drawn about its generalisability, and describes the potential mechanisms through which the women's group intervention may have reduced mortality. Context and mechanisms are summarised in Table 21, and a discussion of these results follows a section on the limitations of the study.

## **8.1 Study limitations**

### ***8.1.1 Sampling bias - place***

Due to concerns over the safety of research staff, two out of the three areas where we collected data were closer to the district centre, and were less remote than other areas receiving the intervention. Despite the possible biased nature of our sample, areas of data collection were not unrepresentative of many areas in Makwanpur or in other districts of Nepal. Therefore the results may be generalisable to similar populations. The study findings are valid in the two areas sampled, and a description of the study context has been provided to enable readers to draw conclusions about external validity.

### ***8.1.2 Sampling bias - people***

During data collection and analysis, it became apparent that we may have a biased sample of *bujne jane manche* (people that understand). Respondents were able to distinguish between these types of people and those who do not understand, but it was difficult for myself and research assistants (as outsiders) to have detailed knowledge of the people in that village, or to have a local understanding of how to define those who do/do not understand. In future research, efforts should be made to consult with local persons to ensure that the experiences and opinions of *nabujne manche* (people that don't understand) are included.

### ***8.1.3 Social acceptability bias***

Respondents may have sought to please the researcher and therefore have reported expected or socially acceptable behaviours and feelings. In the context of this study, this could result in an overly positive projection of the intervention. This type of bias may have particularly affected the responses of men, who may feel unable to express negative opinions about women's groups, or social change, particularly to research assistants evaluating MIRA. Stakeholders may also have been keen to respond positively in order to increase the possibility that they could continue receiving the benefits of employment, and increase the possibility of a further development programme from MIRA.

Social acceptability bias is a difficult limitation to overcome, but I used techniques such as employing a research assistant external to the project, and emphasising that data would be confidential and MIRA employees would not have access to the data. Through multiple visits to the study areas, we felt that a relationship of trust was built between myself, research assistants, and respondents, which also may help to overcome this bias.

Participant observation (as opposed to interviews and focus groups) may have helped to minimise social acceptability bias, but was not possible due to time constraints, and the part time nature of study.

The authenticity of data stating positive findings (that women's groups promoted social, personal and knowledge development, and that the group process facilitated the dissemination of knowledge) is strengthened by the quantity of detailed examples and narratives. Validity of these findings were also strengthened through triangulation of focus group, interview and observation data, and feedback.

#### ***8.1.4 The influence of the researcher***

My identity may have limited the study in two ways: my identity as an adviser to the intervention, and as a white European woman.

##### ***8.1.4.1 Role as an adviser on the project***

My close proximity to the intervention may bias my approach to data collection and analysis. I have attempted to do this through a statement of my role in the intervention and I also took strategies to minimise bias: feedback, generation of themes by an independent researcher, and using research assistants to collect the data. I have also explored how the intervention may have been effective with colleagues and academics, and feel that my in-depth knowledge of the intervention and the context has enabled a better understanding of my findings.

##### ***8.1.4.2 Culture and language***

The effect of cultural and language barriers on cross-cultural research are difficult to overcome. Foreigners are not commonly seen in rural Nepal, and their presence is usually associated with funding agencies for INGO or NGO projects. Foreigners are often perceived as rich, influential, sources of money, and in some instances communities may be suspicious or sceptical of the ‘development’ that they are associated with. Judgements about me, and by me, based on preconceptions, were inevitable. As a well educated, relatively wealthy, European woman I tried to lessen any prejudice that I was an expert, or had superior knowledge by making efforts to be humble, respected local norms during data



collection, dressing in a similar way to the women in the study area, learning words of greeting and common phrases in the local Tamang language. I also recognised that different cultural frames of reference, and power asymmetry between well-educated Nepali research assistants and rural Nepali women needed to be explicitly addressed. I trained researcher assistants about the importance of building rapport, and the importance of stating their lack of knowledge and willingness to learn while they were conducting the research.

Cultural and language differences were addressed by: using Nepali research assistants, transcribing the data in Nepali before translation, using my knowledge and personal experience of living in the district centre of Hetauda for six years, developing good spoken Nepali skills, and consulting with the research assistant/translator for clarification when necessary. I also considered the impact of my presence on data collection during piloting. Feedback of the data to respondents, and discussion of findings with research assistants may also have lessened the influence of cultural misunderstandings on the research.

#### **8.1.5 *Feedback limitations***

I found feedback of results to respondents to be very useful in increasing the validity of findings, and increasing confidence that other forms of bias (social acceptability bias, and personal bias) had been minimised. However, feedback was not easy, and descriptions evolved after each session, progressively making them easier for respondents to understand, and ensuring that they understood the level of abstraction. Research assistants found it difficult to feed back negative feelings or feelings of discontent, and issues of poverty and caste. They were apprehensive about communicating these findings without sounding condescending or judgemental. Sometimes, respondents felt that the research assistant

could not be wrong, because she has lots of experience and she is educated: *[we don't know what to say, those who walk outside the house (like you) can speak but we (village women) cannot]* (WG, feedback notes, Bh). Feedback is also a leading process, which can be problematic: instead of asking open questions, respondents were informed, then asked their opinion. Yet I found it to be very useful when used in combination with other techniques to improve the validity of the results.

**Figure 40 A women's group**

**Photograph taken by Suresh Tamang**



**Table 21 Possible theories explaining the effect of context and successful mechanisms**

<b>Something about Makwanpur (context)</b>	<b>+ Something about the project (mechanism)</b>	<b>= reduced newborn mortality rates</b>
Readiness for social change/on the brink of social change - a population of many people who 'understand'	Trust in implementing NGO	
Positive attitude towards NGOs	Socially acceptable, familiar intervention - not too challenging to gender relations	
Pluralism in the population – the intervention allows for this and therefore is socially acceptable	Women and families became more aware of good care behaviours and carried them out	
Poverty – possible adverse effect on intervention	The intervention created leaders or good role models	
Some caste and gender discrimination, and oppression – possible adverse effect on intervention	Development of self confidence of group members, and lessened feelings of embarrassment about the perinatal period	
Political instability - no routes for participation in political decision making structures	Enabled development of critical consciousness and community action	
	Social networks increased, community capacity increased	

## **8.2 Interpretation**

The following section discusses the way in which the context may have contributed to the effect of the intervention, and compares the contexts of intervention and control areas. An extensive description of the control areas was not possible, but some description of context was possible from the second phase of data collection. Thereafter, the potential mechanisms (or ways in which the intervention is effective) are discussed.

### **8.2.1 Context**

#### *8.2.1.1 Readiness for social change*

The positive attitude towards NGOs and willingness/readiness for social change may have made villagers in the area predisposed to respond well and actively participate in this kind of intervention. Many stakeholders felt that their villages had already experienced some social change, and they were responsive to learning and taking action to improve their health and their situation. Some villagers felt that there were some people who were resistant to change, who held more traditional views, who did not ‘understand’, but these appeared to be fewer in number. Perhaps a context with a critical number of individuals who are willing and enthusiastic for change is necessary for the success of this type of intervention. This is discussed in the community development literature as a level of preparedness is the first rung on the ladder of community based interaction (Laverack, 2007). Laverack states that the level of preparedness can be examined as the readiness or unreadiness to accept change, and readiness to interact with external agents and other members of the community (Laverack, 2007). Other authors suggest that establishing and

sustaining community participation is facilitated when a community has a history of common struggle, and a tradition of voluntarism (Woelk, 1992, Walt et al., 1989).

Respondents in control and intervention areas were largely receptive towards NGOs. Both intervention and control areas appear to be experiencing some social change. Many respondents in intervention areas, men in control areas, and health volunteers in control areas, were particularly motivated to encourage social development in others who did not 'understand'. Women in the control area did not express this motivation to make others 'understand' the value of women's groups and the value of learning new information and knowledge. Women in control areas were also less expressive of experiencing social change than other stakeholders. This could indicate the effect of the intervention on the social context, or it could indicate a baseline difference in extent of interactions with NGOs among women. Some baseline information about extent of engagement with NGOs would be useful to collect in subsequent studies, as would monitoring of extent of engagement with NGOs among women's group members, and non members. Based on the results of this thesis, an intervention with women's groups in Dhanusha, Nepal, studied the attitude of the population towards NGOs at baseline, which may help to explain the results of that intervention (Saville and Morrison, 2006). This finding may imply that communities with a certain level of preparedness may respond well to this type of intervention, and therefore more investment is necessary in communities of lesser preparedness, to develop their capacity. The implementation of this intervention in communities that have less social (and economic) resources to draw upon, may also be more difficult.

In both control and intervention areas, NGOs were perceived as bringing positive change and social development, although there was some evidence of mistrust of NGOs, and expectations that NGOs should provide services and tangible inputs to villages. In contexts that have had largely negative experience with NGOs, it may be difficult to implement this type of intervention. It may also be more challenging to implement this type of intervention in areas where NGOs have provided extensive service or infrastructure inputs, or tangible benefits to villagers, without building their capacity or engaging them in planning, implementation and evaluation of projects. It may be hard to engage communities in this type of intervention, if they are used to being recipients, and not active participants. Conversely, if more motivation and community capacity existed, an area may respond more positively than Makwanpur.

#### *8.2.1.2 Pluralism*

In both intervention and control areas there appears to be pluralism of belief in traditional and allopathic medicine. When respondents were ill, they routinely consulted with a mixture of shamans, private practitioners, and public health personnel. In addition, they also sometimes sought advice from friends and neighbours. Research has shown that this multiple use of service providers is common (Dhungel, 1992, Erickson, 1995, Desjarlais, 1992, Dhakal et al., 2007, Kafle et al., 1996, Hotchkiss, 2001). Although respondents felt that some villagers still relied exclusively on traditional medicine, this was due to poverty, the high cost of seeking and receiving services, as well as cultural preferences and definitions of illness and healing. Within this context, a participatory intervention that allowed for discussion about appropriate services was perhaps the most feasible. It is

evident that respondents were open to using public health services if the quality was good, and the intervention was socially acceptable in this context.

### *8.2.1.3 Attitude towards health services*

Dissatisfaction and mistrust of health services was similar across intervention and control areas. Within this context it is interesting that statistically significant differences between intervention and control areas were observed for care seeking during any illness of the mother or baby (50% and 22%, and 24% and 10% respectively), institutional deliveries (7% and 2%), and births attended by a government health provider (9% and 3%) (Manandhar et al., 2004). If this intervention were repeated it may be helpful to monitor the quality of health services over time, in intervention and control areas, to help in explaining the results. The quantitative findings indicate that even in areas where health services were largely considered sub-standard by communities, a participatory intervention may be successful in increasing demand for services. Yet process data collected in this study demands that these findings are further unpacked and explored. The low numbers of institutional deliveries and deliveries attended by government health workers indicate that participatory approaches supplemented by health systems improvements, could have a larger effect than community mobilisation alone, on mortality and process indicators.

The lack of trust in health services also suggests that the women's groups have made minimal impact on improving health services. Unlike the Warmi study, communities were unable to leverage significant change in the delivery or quality of health services (Howard Grabman, 1996). It is not clear what resources were available to the women's groups in the Warmi project, nor is there a full description of all the strategies developed by the groups. It



is possible that financial support was provided to groups in Warmi, and this may have affected ability to leverage change.

Stakeholders in Makwanpur expressed a sense of powerlessness, or apathy, in relation to improving health services, and the intervention appeared not to engage stakeholders with health services beyond their status as clients. This study suggests that communities perceive themselves to be receivers of health services, as opposed to having an active role in the planning or provision of services. This may be true of community stakeholders in many contexts, but what may be different in this context is the perception that it may be unreasonable to demand services from overburdened and incapable health workers (Stone, 1986). Stakeholders had low expectations and in many instances avoid the use of local services.

#### *8.2.1.4 Context of political instability*

The mistrust in health services and the lack of engagement with health services by the groups and communities, may be partly due to the political instability that affected the study area. Local government structures were nonexistent, and therefore the overall management of local health facilities was brought to the District level. Management committees of local health facilities were not functioning well in the study area prior to the implementation of the intervention, but they were a possible route to community participation in the planning and implementation of services. Without local political structures and representatives, it would have been difficult for communities or women's groups to engage with management committees, or contribute to the re-organisation and revitalisation of management committees. Interestingly, women's group members, or other

stakeholders, did not mention management committees as a way of improving services. In this context of lack of local democratic structures, and political oppression it may have been difficult for communities to engage with broader power structures. The intervention appeared to be effective despite this context, and a lack of engagement with societal and political power structures. The literature suggests that political commitment is an important facilitator for effective community participation to improve health and therefore it is perhaps not surprising that in this relatively unsupportive environment, broader issues of power were not addressed (Walt et al., 1989, Howard Grabman and Storti, 2007, Gonzales et al., accessed 2007). This will be further discussed while considering the mechanisms of the intervention.

#### *8.2.1.5 Caste and gender inequalities*

Although many respondents in intervention and control areas felt that there had been social change, caste and gender differences affected social interactions and social life in intervention and control areas. The fact that the intervention appeared effective in this context of inequity may be unexpected and considered positive. This context may have hindered the intervention to some degree, and more conducive contexts may induce even more positive effects. The participatory nature of the intervention enabled stakeholders to challenge, or work around social norms and inequalities. Perhaps in contexts with more strict gender or caste discrimination, this intervention may not be as effective. The Tamang ethnic group dominated the study area. They are largely Buddhist, and are viewed as more egalitarian than other ethnic groups (Holmberg, 1989). Most marriages are not arranged, and are by mutual agreement. The number of scheduled caste groups in the area was low,

and therefore there was lower potential for caste discrimination against these groups to affect an intervention in this area.

The context of a lack of openness in communications between men and women, and the social context of lack of explicit male involvement in perinatal care (which existed in both intervention and control areas) may have affected receipt of the intervention. The observed effect could have been suboptimal, and a subsequent intervention in Malawi has discussed some male involvement at the problem prioritisation stage of the intervention (Maimwana, 2004). The intervention appears socially acceptable, as it did not explicitly challenge assumptions and social norms about the perinatal period being the domain of women. The groups were exclusively female, and village men were only asked to participate in the implementation of strategies, perhaps in roles with which they already felt comfortable.

#### *8.2.1.6 Poverty*

Although the area was poor, the intervention still appeared to be successful. The intervention may have had a greater effect on neonatal survival if it was implemented in areas with better resources. Both intervention and control areas felt that life was difficult and there were few opportunities for advancement. Baseline socioeconomic status data, and district government data, from intervention and control areas shows that intervention areas have better indicators of development than control areas (District Development Committee, 2006). This may affect the interpretation of quantitative data showing differences between intervention and control areas. The intervention was conducted in an area that scored around middle of the human development index in Nepal, and this is also important to note. There were expectations from villagers that MIRA should provide services and tangible

benefits, and this made it more challenging to implement the intervention. This study suggests that a certain minimal level of resources may be necessary for this intervention to be successful.

### **8.2.2 Mechanisms**

#### *8.2.2.1 Trust in implementing NGO*

The methodology of the intervention and the attitude of employees of MIRA may have been a part of the mechanism that made the intervention effective. Respondents stated that they appreciate interactions with those who move around a lot, or persons external to the village, because they bring new knowledge and a different perspective. If these interactions are with individuals who are trustworthy and respected, and have a good working style (as perceived by villagers) then these interactions can be more effective and positive. In their manual 'How to mobilise communities for health and social change', Howard Grabman and Snetro (Howard Grabman and Snetro, 2003) suggest preparing the community for social change by: orienting the community, building relationships, establishing trust, credibility and a sense of ownership with the community, inviting community participation and developing a "core group" from the community to lead the effort on behalf of the community. Although it was not mentioned by respondents in this study, project managers, principal investigators and technical advisors to the project feel that formative research and training of employees was important in establishing relationships with communities, developing a learning attitude in employees, and in developing an appropriate intervention (Morrison et al., 2008a). Stakeholders did find MIRA employees to be trustworthy, knowledgeable, hardworking and treat them with respect, and this was a specified aim of

training and formative research. Howard Grabman (Howard Grabman, 1996) also hold that the attitude of project staff was important in facilitating and maintaining a participatory approach, led by communities. Other authors also emphasis the importance of being sensitive and humble in effectively mobilising communities (Morgan, 2001).

#### *8.2.2.2 Social acceptability of the intervention*

The intervention itself was familiar to respondents, who had had experience with community groups led by NGOs. The fact that these community groups were for women, was also uncontroversial, as maternal and newborn health was perceived as a female domain. The intervention was not challenging to this social norm.

The participatory nature of the intervention also allowed for local concepts of pluralism and traditional practices to be incorporated according to the wishes of the group. Strategies sometimes sought to promote traditional practices, or train shamans (Morrison et al., 2005a). The use of local female facilitators also enabled the intervention to be socially acceptable, as new concepts were integrated with understanding and empathy for traditional practices, and there appeared to be genuine ‘learning together’ of employees (facilitators) and communities.

#### *8.2.2.3 Dissemination of knowledge*

The data suggest that there was dissemination of knowledge by facilitators, group members, and those participating in the intervention, to others in the community. Group members influenced the knowledge, care practices and care-seeking behaviour of non-group members. The evidence presented in this thesis also demonstrates that women disseminated

what they had learned to other community members. Women's group members perceived themselves as facilitators of social change, and health workers and community leaders perceived NGOs, including MIRA, as supporting their leading role in helping to bring social change. A report detailing the results from one women's group meeting about the representativeness of women's group members revealed that only 8% of married women of reproductive age in the study area attended groups (Morrison et al., 2005b). In intervention areas, only 37% of newly pregnant women joined the groups (Manandhar et al., 2004). Another study also revealed that, women in the intervention areas were more likely to change from bad to good care behaviours, than women in control areas (Wade et al., 2006).

Diffusion of innovation theory suggests that 'early adopters' select the innovation first, followed by the majority, until the innovation is common. For innovations to be adopted, individuals must go through stages of: knowledge of an innovation, forming an attitude towards the innovation, taking a decision to adopt or reject the innovation, implementation of the new idea and confirmation of this decision (Rogers, 2003). Research has shown that the relationship between the source of communication and the receiver of information, is more important than the perceived scientific or technical merits of the innovation. The more similar the source of information to the potential adopter, the faster the adoption of the innovation (Lundblad, 2003). Opinion leaders are often used to stimulate adoption of the innovations by the wider population, as they have certain similar attributes to the average person but may be of slightly higher status, be more educated or more cosmopolitan (Rogers and Shoemaker, 1971, Greenhalgh et al., 2004).

In the context of this study, facilitators and MIRA employees may fit this definition of opinion leaders able to facilitate change. Stakeholders defined employees as trustworthy sources of knowledge, and people who had more extensive social interactions and travelled outside the immediate locality. Facilitators felt that they had learned and personally developed through their involvement in the intervention. They also felt that their social standing had increased in the community. This finding is supported by a descriptive study where facilitators were called to attend trainings by other NGOs as their social status increased, and it became acknowledged that they had access to large numbers of women in the community (Morrison et al., 2005a). Perhaps women's group members were also perceived to be more cosmopolitan, people who 'understand', and therefore dissemination of information by them, or diffusion of innovation, may promote widespread adoption of good care behaviours. More in-depth study of the characteristics of women's group members is necessary to explore this hypothesis. This theory has been applied to health promotion and is discussed as a theory underpinning peer education for health promotion (Moser and Mosler, 2008, Tones, 1997, Turner and Shepherd, 1999). This is a possible mechanism through which the intervention may have worked, which could be explored further in future research. It is unlikely, however that *only* this dissemination of knowledge mechanism explains the trial result. Formative research showed that although there were some knowledge gaps, the constraints on accessing services, and constraints to practising good care behaviours sometimes prevented women or families from acting on their knowledge. The extent to which good care behaviours were 'innovations' may also be debateable.

Social learning theory also emphasises the importance of role models, where subjects observe behaviours taking place and then go on to adopt similar behaviour. According to Bandura, subjects need an opportunity to practice modelled behaviour and positive reinforcement (praise or social acceptance) if this is to be adopted successfully (Bandura, 1977, Ormrod, 1999). Only some of the women's group members became pregnant during the study period, and therefore they did not have the opportunity to practise modelled behaviour. Also, only some of the facilitators were married with children, and therefore they have not been able to demonstrate (model) behaviours for others to adopt. They may have modelled personal development through their involvement with NGOs, which may have encouraged other women to join groups and participate in the intervention. Female MIRA employees (largely facilitators, and WE's), may also have been positive role models, purely by their ability to walk around independently and to be employed, earning money. Focussed study, perhaps through a biographic methodology, would be useful to explore the role of facilitators in the effect of the intervention. The small sample size and the more general focus of this study make it difficult to draw conclusions about the effect of the facilitator. Research is being conducted in a similar intervention in a slum of Mumbai that explores the role of the facilitator in the effect of the intervention (Alcock, 2007).

#### *8.2.2.4 Development of knowledge and self confidence*

The intervention enabled the development of knowledge and self confidence, among women attending the women's group, among community members, and facilitators. Particularly women attending the group felt they had learned, and personally developed through their interactions with MIRA and with other women. Some baseline qualitative data were collected on knowledge of danger signs and knowledge of appropriate care



behaviours during the perinatal period (Mesko et al., 2003, Tamang et al., 2001). These data suggested that there was some knowledge about perinatal care, although it varied across ethnic groups. This previous study also found that knowledge was not always acted upon due to other constraints, such as poverty. It would seem feasible that MIRA employees and discussions with other group members in the groups, reinforced knowledge that community members may have already received through media, education, other training by NGOs, or NGO workers. There was some evidence that women attending the group became more confident, and they felt less embarrassed discussing issues around pregnancy, birth and the postpartum period. Data from men also indicated that knowledgeable women perhaps have more status (or gain more respect) within the household, although it is not clear how their status would be affected if they challenged household decisions based on their new knowledge. A study of the Maternal and Child Health Funds also supports findings about increased self confidence among group members, and an increased feeling of personal control (Morrison et al., 2008b).

The development of individual self confidence and competence increases perceptions of personal control, which can have a direct effect on health outcomes (Wallerstein, 1992). Yet women and families do not take decisions about their health in a social vacuum, the opportunity structure also constrains and influences decision making (Bunton et al., 1991, Kabeer, 1999, Steckler et al., 1995). Structure can constrain individual agency and it is not inevitable that having internal or intrinsic power leads to greater community control over resources. Much of the empowerment literature suggests that the development of individual self-confidence is one part of creating empowered communities that can enable social or behavioural change. For example, according to Torre (1986, referenced in (Rissel,

1994), there are three essential components of community empowerment, micro factors (intra-personal aspects such as development of self-esteem and self efficacy), mediating structures (the group mechanism whereby members through their active participation shared knowledge and raised their critical consciousness) and macro factors (political and social activities). All three of these factors need to be present for community empowerment, and thus improved health outcomes, to occur.

#### *8.2.2.5 Development of a critical consciousness and community action*

This study provides evidence of an increased awareness of maternal and neonatal health problems, and increased knowledge of good care behaviours that stakeholders often attributed to the intervention. Both intervention and control areas were experiencing some social change, and therefore the collection of baseline and longitudinal data in intervention and control areas would enable the validity of this finding to be strengthened. It is interesting to note that women in control areas did not experience social change, as compared to intervention areas where women experienced social change more than men. Comparative longitudinal data would strengthen conclusions about differences between intervention and control areas. There is evidence that a critical consciousness was developed, a deeper understanding of maternal and newborn health issues was gained, which is considered necessary in order for participants to take action to improve their situation. Women's groups, and communities, took action to deal with their problems, and this thesis shows that the action taken also enabled more people to become involved and aware of the issues. This thesis shows that taking action increased critical consciousness further, and increased action. The actions taken (or strategies implemented) by women's groups and some community members - the clean home delivery kits, funds, stretchers and

video shows - enabled links to be made with other community groups and community members. Women's groups mobilised resources from the wider community to implement strategies and also linked with existing groups and key individuals (such as community health volunteers, ex-VDC chairpersons and PLAN community groups) to disseminate information about strategies and access resources. There is also some evidence that community links with health services may have improved through the development of knowledge about availability of services, and knowing the identity of health volunteers, supporting health workers and encouraging women to use existing services.

Since this thesis research was conducted there has been increased mobilisation of resources, and groups have linked with other organisation to organise community events promoting newborn and maternal health. They have also mobilised resources for MCH funds by making them community funds as opposed to group only funds (Neupane and Morrison, 2007). This collaboration and increased development of social networks or access to social networks may have created a more cohesive society and built capacity of communities to work together in addressing problems, but further focussed research is necessary to explore this issue. The developments since the conduct of this study also reinforce the importance of conducting long-term interventions and collecting data over time to explain their effect.

Much of the empowerment literature supports these findings. The progression from developing knowledge, gathering information, gaining self confidence, developing skills, organising to take action, and taking action, combine to have an empowering effect. Freire argues that there is no fixed or standardised way of generating information, but the important thing is to use a way that enables people to turn information and knowledge into

power (Rifkin and Pridmore, 2001). Empowered community based organisations are thought to be the essential link between empowered individuals and effective political action (Israel et al., 1994). Community based organisations can enable the development of skills and capacities to enable communities and individuals to act to improve their situation, and achieve better health outcomes. They can do this through the development of knowledge, skills and social support (Laverack, 2007). Laverack, Labonte and Rissel convey this as a dynamic continuum, progressing from individual empowerment, small group participation, community organisation, partnership, to political action (Rissel, 1994, Labonte, 1990, Laverack, 2001). This links self-efficacy, community capacity and community cohesiveness and context, that allows participants to move towards political action (Laverack, 2001).

This study has shown that communities did not engage with broader political and social power structures, and perhaps this intervention could be criticised for its failure to enable broader power struggles to be tackled, therefore doing little to address the links between social inequality, empowerment and health at a higher level. Some may argue that empowering processes to improve health outcomes were limited in scope in this intervention. The primary health care movement was also often criticised for achieving small-scale successes, but failing to tackle fundamental national power differentials. The political context of the intervention has been described and discussed, and this may have been a constraint to broader political action. Nonetheless, improvements in health were observed, and I propose that this intervention may have been effective through the development of enough capacity to provoke or support change at a household level, and

begin to change social norms of appropriate behaviour. This appears to have been sufficient to affect positive behaviour change for newborn survival.

**Figure 41 A community examining their stretcher**

**Photograph taken by Tom Kelly. The stretcher was bought as a result of the community planning meeting organised by the women's group**



## **9 Conclusions and Recommendations**

The evaluation of interventions using a randomised controlled trial design may be the most rigorous way to evaluate the efficacy of an intervention, but it also has its weaknesses. The most well documented weaknesses are its focus on outcome alone, an inability to explain trial results, and an inability to examine the external validity of the results (Wight and Obasi, 2003). If trials are conducted with integrated, concurrent process evaluations, this may go some way to addressing the weaknesses of the RCT. Process evaluation is an emerging approach, drawing on realistic evaluation methodology, that can offer information on implementation, effect of context and can help to explain the results of trials (Stephenson et al., 2003). This thesis supports calls for the integration of concurrent process evaluations within randomised controlled trials.

This thesis has provided information that helped to explain the results of an RCT of a participatory intervention using women's groups to reduce neonatal mortality. Conclusions could be strengthened by the collection of baseline data, and data collection over the implementation period of the intervention – in both intervention and control areas.

Nonetheless, some conclusions can be drawn that may inform the development of similar interventions, and help to explain the trial result. There has been some scepticism about the ability of this type of intervention to reduce neonatal mortality at the community level in a resource poor setting (Costello, 2006), and there have been calls to explain the results of the Makwanpur trial. This study contributes to an emerging evidence base for community based participatory interventions particularly for maternal and neonatal health.

## **9.1 Explaining the results of the trial**

### **9.1.1 *Women's groups***

This thesis proposes that the women's group intervention was successful in enabling learning and development of knowledge in the women participating in the group, and in the wider community. The way that knowledge was gained, stimulated group participants to disseminate information about maternal and neonatal health to other women. Community planning and implementation of strategies to address prioritised problems also enabled dissemination of information. Importantly, planning and implementation of strategies enabled groups to access and mobilise community resources, and community social networks. This may have strengthened community capacity to address problems, and also developed increased awareness of maternal and neonatal health. This increased awareness and *owned* knowledge may have led to changes in behaviour. These findings support Paulo Freire's theories of learning, and empowerment through building a critical consciousness (Freire, 1972). Other authors have also found that involvement with community based organisations and social networks has an empowering effect communities, and may be linked with better health outcomes (Laverack, 1999b, Laverack, 2001, Wallerstein, 2006).

### **9.1.2 *Health services***

Planning and implementation of strategies only led to a limited interaction with health service providers, and there was some evidence that the intervention helped to revitalise community health volunteers. However, this thesis shows that there was little improvement in health services (or improved perceptions of health services), as a result of the intervention. Improvements in newborn survival may be to a greater extent related to changes in behaviour within the household (Manandhar et al., 2004).



### **9.1.3 MIRA**

The implementing organisation was important in the success of the intervention. The women's group intervention was implemented in the way it was intended. The trial team were committed to taking a participatory approach, and gained the confidence of communities. They also disseminated knowledge about maternal and neonatal health, and became perceived as knowledgeable, trustworthy, respected individuals by communities. This has implications for scale-up and implementation of this intervention in other areas, in terms of development of a committed, confident team, accepted and trusted by communities.

## **9.2 External validity of trial findings**

Communities in intervention areas were positive and responsive to NGOs, which may have affected the receipt and response to the intervention. The intervention was feasible and acceptable in this context as maternal and neonatal health is perceived to be the domain of women, and community groups were an accepted way to gain knowledge, personally develop, and help the community progress. Communities (and particularly women) were experiencing social change in intervention areas, and despite the fact that caste and gender discrimination were present, many appeared to be responsive to changes. The participatory nature of the intervention also aided its acceptability, for example, facilitators were able to initiate discussions without contradicting the plural faith in allopathic medicine and shamans.

This trial was conducted during a time of civil unrest and dissolution of local and national democratic structures. Therefore, the ability of women's groups and communities to engage with local or national power structures was curtailed. In a more stable political context, this type of intervention may stimulate interaction with power structures.

The socio-economic status of the population and previous experience with NGOs providing tangible rewards, made the implementation of this type of intervention challenging, but still possible. In better-off contexts, or in contexts with less dependency on NGOs, this type of intervention may be better received.

### **9.3 Areas for further research**

Globally, there has been a movement to research the effectiveness of community based participatory interventions for newborn and maternal survival ([www.towards4and5.org.uk](http://www.towards4and5.org.uk), 2007, Bhutta et al., 2005). The conduct of mixed method integral process evaluations can help to explain the results of outcome evaluations, and additional studies in Malawi, India and Nepal have been collecting process data for this purpose. These process evaluations should consider a) the context in which the intervention is delivered; b) the extent and quality of implementation of the intervention; c) the mechanism by which the intervention is assumed to work; and d) the differential responses of the target population.

Future process evaluations may also benefit from collecting data to measure or describe empowerment of women and communities, and to describe if and how social networks are developed. Detailed data collection about the development and implementation of

strategies may be beneficial, and this could be linked to the analysis of outcome data.

Baseline data about the perceptions of stakeholders about NGOs, may also help to explain outcomes.

A comparison of women's group members as compared to other women in the study area may help consideration of the type of women being engaged in the intervention. For example it would be interesting to find out to what extent the intervention was involving poorer or more marginalised community members. Future research should be mindful of sampling individuals or groups who are considered less cosmopolitan or considered to be less well developed (those who do not 'understand'). Longitudinal analysis of outcomes and experiences of stakeholders at specific times - that are linked to the intervention - may also help to interpret how aspects of the intervention relate to care behaviours and perceptions.

In future process evaluation research, it may be beneficial for principal investigators and the research team to prepare a list of statements describing the ways in which it is hypothesised that an intervention may work, as suggested by Sutton, and Pawson and Tilley (Sutton, 2003, Pawson and Tilley, 1997). The theory base of this women's group intervention referred to the work of Paulo Freire's theory of learning, but this was not developed or deconstructed further by the trial team. This could help to focus future process evaluations and help plan sub-group analysis. The findings of this thesis could feed into the design of future process evaluations, and discussions about mechanisms and contextual effects. It may also be beneficial to conduct discussions with women's groups and

community stakeholders about trial results, as this may help explain their effectiveness or ‘failure’.

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## **Appendix 1 Inclusion and Exclusion criteria**

Stakeholder or place	Inclusion criteria	Exclusion criteria
Ward	<p>Wards should:</p> <ul style="list-style-type: none"> <li>• Reflect the different activeness of women's groups</li> <li>• Reflect the different locations of women's groups in terms of remoteness and distance from a bazaar</li> <li>• Be part of the MIRA study area, selected to receive the intervention</li> <li>• Be in different Village Development Committees</li> <li>• Have facilitators who have worked since the beginning of the study</li> <li>• Be defined as secure by MIRA project manager</li> </ul>	<ul style="list-style-type: none"> <li>• Wards that are politically insecure and dangerous as defined by MIRA project manager</li> <li>• Wards outside the MIRA intervention area</li> <li>• Wards with a facilitator who was recruited after the study started.</li> </ul>
Women's group members	<ul style="list-style-type: none"> <li>• Women should have attended the MIRA mothers group regularly</li> </ul>	<ul style="list-style-type: none"> <li>• Women who have not attended MIRA mothers group meeting</li> </ul>
Mothers in law (not attending meeting)	<ul style="list-style-type: none"> <li>• Mothers in law who have not attended MIRA women's group meetings</li> <li>• Mothers in law that live in the ward being studied, and have lived there since the beginning of the intervention</li> </ul>	<ul style="list-style-type: none"> <li>• Mothers in law that have attended mothers group meetings</li> <li>• Mothers in law that live outside the ward</li> <li>• Mothers in law that are health workers, community leaders or facilitators</li> </ul>
Married women of reproductive age (MWRA not attending meetings)	<ul style="list-style-type: none"> <li>• Aged 15-49</li> <li>• Married women with children and unmarried women will both be invited to participate</li> <li>• Do not currently attend MIRA women's groups</li> </ul>	<ul style="list-style-type: none"> <li>• Women who regularly attend the women's group meeting</li> <li>• Women who are younger than 15 or older than 49 years old</li> <li>• Women that are facilitators or health workers</li> </ul>

Stakeholder or place	Inclusion criteria	Exclusion criteria
Men	<ul style="list-style-type: none"> <li>• Married men</li> <li>• Men whose wives or family members attend MIRA women's group meeting</li> <li>• Men whose wives do not attend MIRA women's group meeting</li> <li>• Men who live in the ward</li> </ul>	<ul style="list-style-type: none"> <li>• Men who live outside the ward (including those whose home is in the ward but their work keeps them away for the majority of the time)</li> <li>• Men who are health workers or community leaders</li> </ul>
Community health volunteers	<ul style="list-style-type: none"> <li>• Government recruited traditional birth attendants and female community health volunteers.</li> <li>• Volunteers that live in the ward for the majority of the time</li> </ul>	<ul style="list-style-type: none"> <li>• Volunteers who are not normally present in the ward</li> </ul>
Government health workers	<ul style="list-style-type: none"> <li>• Village Health Workers and Maternal Child Health Workers from the health facility in the VDC of data collection</li> </ul>	<ul style="list-style-type: none"> <li>• Other health staff</li> </ul>
Facilitator	<ul style="list-style-type: none"> <li>• Facilitator who has worked for MIRA for the duration of the project</li> </ul>	<ul style="list-style-type: none"> <li>• Facilitators that have been employed recently by MIRA</li> </ul>
Community leader	<ul style="list-style-type: none"> <li>• A person defined as important members of the community by women's group members</li> <li>• A person that lives in the ward</li> </ul>	<ul style="list-style-type: none"> <li>• Health workers</li> <li>• Live outside of the ward</li> </ul>

**Appendix 2 Publication – Morrison et al. How did formative research  
inform the development of a women’s group intervention in rural Nepal?**























**Appendix 3 Publication – Morrison et al. Women’s health groups to  
improve perinatal care in rural Nepal**

## Research article

## Open Access

### Women's health groups to improve perinatal care in rural Nepal

Joanna Morrison<sup>\*1</sup>, Suresh Tamang<sup>2</sup>, Natasha Mesko<sup>1</sup>, David Osrin<sup>1</sup>,  
Bhim Shrestha<sup>2</sup>, Madan Manandhar<sup>3</sup>, Dharma Manandhar<sup>2</sup>, Hilary Standing<sup>4</sup>  
and Anthony Costello<sup>\*1</sup>

Address: <sup>1</sup>International Perinatal Care Unit, Institute of Child Health, University College, London, 30 Guilford Street London, WC1N 1EH, UK;  
<sup>2</sup>Mother and Infant Research Activities (MIRA), CPO Box 921, Kathmandu, Nepal, <sup>3</sup>Nepal Administrative Staff College, Kathmandu, Nepal and  
<sup>4</sup>Institute of Development Studies, Falmer, Brighton, Sussex, BN1 9RH, UK

Email: Joanna Morrison<sup>\*</sup> - [j.morrison@ich.ucl.ac.uk](mailto:j.morrison@ich.ucl.ac.uk); Suresh Tamang - [mira@vianet.com.np](mailto:mira@vianet.com.np); Natasha Mesko - [n\\_mesko@hotmail.com](mailto:n_mesko@hotmail.com);  
David Osrin - [d.osrin@ich.ucl.ac.uk](mailto:d.osrin@ich.ucl.ac.uk); Bhim Shrestha - [mira@vianet.com.np](mailto:mira@vianet.com.np); Madan Manandhar - [m.manandhar@info.com.np](mailto:m.manandhar@info.com.np);  
Dharma Manandhar - [dsm@healthnet.org.np](mailto:dsm@healthnet.org.np); Hilary Standing - [h.standing@ids.ac.uk](mailto:h.standing@ids.ac.uk); Anthony Costello<sup>\*</sup> - [a.costello@ich.ucl.ac.uk](mailto:a.costello@ich.ucl.ac.uk)

<sup>\*</sup> Corresponding authors

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## Abstract

**Background:** Neonatal mortality rates are high in rural Nepal where more than 90% of deliveries are in the home. Evidence suggests that death rates can be reduced by interventions at community level. We describe an intervention which aimed to harness the power of community planning and decision making to improve maternal and newborn care in rural Nepal.

**Methods:** The development of 111 women's groups in a population of 86 704 in Makwanpur district, Nepal is described. The groups, facilitated by local women, were the intervention component of a randomized controlled trial to reduce perinatal and neonatal mortality rates. Through participant observation and analysis of reports, we describe the implementation of this intervention: the community entry process, the facilitation of monthly meetings through a participatory action cycle of problem identification, community planning, and implementation and evaluation of strategies to tackle the identified problems.

**Results:** In response to the needs of the group, participatory health education was added to the intervention and the women's groups developed varied strategies to tackle problems of maternal and newborn care: establishing mother and child health funds, producing clean home delivery kits and operating stretcher schemes. Close linkages with community leaders and community health workers improved strategy implementation. There were also indications of positive effects on group members and health services, and most groups remained active after 30 months.

**Conclusion:** A large scale and potentially sustainable participatory intervention with women's groups, which focused on pregnancy, childbirth and the newborn period, resulted in innovative strategies identified by local communities to tackle perinatal care problems.

### Background

Participatory approaches to health have been advocated since the 1978 Alma Ata declaration in which the World Health Organisation emphasised the need for citizen participation in primary health care [1]. This paper details the development and implementation of a participatory project to improve perinatal care at the community level in rural Nepal.

### Community participation in health care

The vision of Alma Ata was that increasing community participation in planning and implementation would lead to more cost-effective delivery of health care and increases in service utilisation. As communities took greater ownership of services they would become more culturally acceptable and responsive to local needs. Community participation also aimed to increase self-reliance and social awareness, which would lead to better health outcomes [2-4]. Opinions differ about the extent to which participation can achieve these results, and to what degree governments and agencies have facilitated participation, but the appeal of participatory approaches remains strong. Participation may be considered as a continuum [5]. In fully participatory approaches, needs are identified by the community themselves, who then may seek external support. At the other end of the continuum, superficial participation of community representatives is sought to validate the aims of programme planners, usually already decided.

### Harnessing the strengths of participation in community based interventions

Reproductive health is an area where participatory approaches have been attempted. A structured literature search for community-based interventions focusing on perinatal health revealed no randomized, controlled trials, but two studies in developing countries which had evaluated impact on Perinatal health outcomes. The Warmi project in Bolivia, initiated by a collaboration of Save the Children Federation, USA and USAID Mother-Care project [6], worked with women's groups to reduce maternal and neonatal mortality and morbidity. They used a participatory approach involving community diagnosis, planning together, implementation of plans, and participatory evaluation. The Warmi project, though neither randomized nor controlled, and based on a before-and-after analysis of 639 and 708 births, did report a reduction in the perinatal mortality rate from 117 to 44 per thousand births. The activities initiated by women's groups included literacy programmes, savings and credit schemes, and programmes to increase access to family planning.

Studies based in the community that are towards the low end of the participation continuum also appear to have

been successful in enabling improvements in pregnancy outcomes. A study in Maharashtra state, India, tested the effectiveness of early detection of warning signs of illness and village level management of neonatal sepsis (a cause of many neonatal deaths in developing countries) [7]. Village health workers were trained to visit newborn infants in their homes and identify and treat neonatal sepsis. This intervention appeared highly successful as a drop in neonatal mortality of 62% occurred. Village health workers were intensively managed and supported by the research team, and therefore large-scale implementation may be difficult. The study did, however, provide evidence that community level interventions to prevent or treat problems of the perinatal period in developing countries could be cost-effective.

### The Nepal MIRA Makwanpur trial

The MIRA Makwanpur trial was designed to test the impact on neonatal mortality of a participatory intervention with women's groups, based on the Warmi Bolivia model, but on a much larger scale and using a randomized and controlled design. In south Asia infant mortality rates fell steadily from 1970 to 1990, but the decline has subsequently plateaued. In order to reduce infant mortality rates further, a focus on the neonatal period, in which most infant deaths occur, is necessary [8,9]. Primary and secondary care are deficient in rural areas of Nepal and where services exist, the reasons for their underuse are complex. The topographical barriers combined with limited expenditure on public health, poor quality of care, a high turnover of service providers, a lack of drugs and supplies and a lack of ownership of health programmes by communities all contribute to issues of demand and supply.

The trial was implemented by a Nepali non-governmental organization, MIRA (Mother & Infant Research Activities). MIRA has been working in Nepal since 1992, conducting research specifically about newborn care, and is headed by a senior pediatrician (DM). The trial involved 24 Village Development Committees in rural Makwanpur district. Ethical approval was sought from the Nepal Health Research Council, and local meetings were held with the District Development Office and Chief District Officer to discuss the aims and objectives of the study. The chairpersons for each Village Development Committee agreed to take part in the study and provided signed consent, and links were made with community leaders, district health services and non governmental organisations. Each Village Development Committee has an average population of 7000 (range 1576 to 23 429) divided between nine wards. In twelve of the Village Development Committees a trained, locally based facilitator was employed to mobilize women's groups. All pregnancies and births to married women of reproductive age were monitored in the

community. Details of the monitoring and the design of the trial have been described elsewhere [10] and the effect of this intervention on birth outcomes was reported in a recent publication [11]. Astonishingly, there was a reduction in neonatal mortality by 30% in intervention clusters, and an even larger and statistically significant effect on maternal mortality rates (78% reduction), although caution is required in interpretation given the relatively few maternal deaths. This paper describes and analyses the implementation of the first stages of the participatory intervention over a 30 month period.

## Methods

### Setting of intervention

Nepal has a population of 23 million and a per capita gross national product of 240 US dollars. Literacy rates have improved steadily, particularly for females (currently 43%), but there remain gender disparities in literacy, school enrolment, and school dropout rates [12].

Life expectancy is now 61 years [13]. The total fertility rate is 4.1, the under-five mortality rate 91, the infant mortality rate 64, the neonatal mortality rate 39 per thousand live births, and the perinatal mortality rate 47 per thousand births [9]. The maternal mortality ratio is estimated at 539 per 100 000 live births [14]. Access to health care is limited as a result of geography, limited expenditure on public health, variable quality of care, high turnover of service providers, a lack of drugs and supplies, and lack of ownership of health programmes by communities.

Makwanpur district, south west of Kathmandu, has a population of 376 000 [15] and a Human Development Index of 0.31, close to the national median. Makwanpur comprises hill and plain areas, with 15 different ethnic groups, the largest being Tamangs, a Tibeto-Burman group. Data from our baseline survey showed that more than 90% births take place at home and only five percent are attended by a trained birth attendant. The first health care provider in times of maternal or neonatal illness is the shaman (*dhami jhankri*) or traditional healer [16].

### The intervention process

The first ten meetings of the women's group participatory intervention were based on the design of the Warmi project in Bolivia [17]. In order to enter the communities successfully we gathered detailed information on local social networks and organizations, as well as attitudes and practice around the time of pregnancy and birth. Social mapping and qualitative research were conducted and served as a training exercise in facilitating focus group discussions and building rapport in the community [18].

### Establishing facilitated women's groups

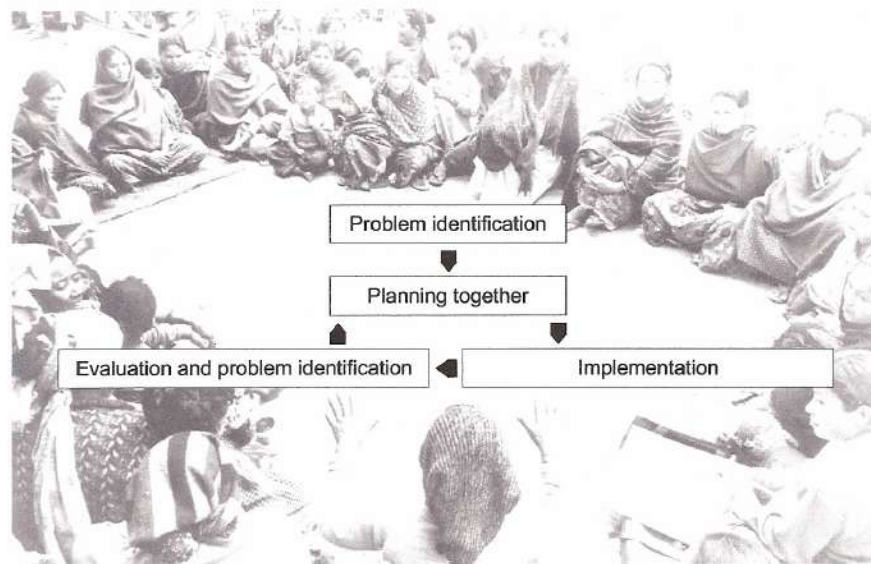
Meetings were facilitated by a paid, locally based woman, who was selected on merit and trained in facilitation techniques. The position of facilitator was locally advertised and suitable candidates were interviewed by senior MIRA employees. Each facilitator is paid a salary slightly higher than the government equivalent (5330 Nepalese rupees, or 71 US dollars). Her full-time responsibility was to plan and facilitate monthly women's group meetings, each facilitator leading nine groups per month, covering an average population of 7000. Meetings were organized in co-ordination with the local Female Community Health Volunteer, an unpaid community based health worker. In profiling our study area, we found that nongovernmental organisations or community based organisations did not routinely work in all 24 of our study Village Development Committees and had different agendas. The female community health volunteer works at ward level, and as part of her job description she runs women's groups to conduct health promotion activities.

The facilitator used a meeting manual, adapted from the Warmi project, to guide the women's groups through problem identification and community planning using participatory iterative methods (see Figure 1 and Table 1). Facilitators were trained in the use of this manual and were allowed scope for their own input. Facilitation supervisors were also appointed after national advertisement and formal interview, and two men and three women were selected. One supervisor was provided for every three facilitators, providing support through community visits and regular meetings.

### First meetings and problem identification

Facilitators and supervisors were responsible for creating awareness and interest in their communities about the meetings, and in most wards at least 20 women attended the first few meetings (see Figure 2). Time was taken to introduce the study agenda to the groups, especially important in areas where many non governmental organisations work and expectations were often high. The first three meetings facilitated discussion of the reasons why mothers and newborn infants die in the community. The reasons for death were discussed in terms of social as well as medical factors with the aid of a story [19]. Women were introduced to the concept of 'learning together' through another story, and were encouraged to discuss perinatal problems within the group and with their neighbours and friends. In this way the facilitator and the women learned which perinatal problems affected their community. Each group prioritised three problems of newborn infants and/or pregnancy which were recorded with justification for their inclusion. Most group members were illiterate and therefore facilitators used pictures and voting with stones to prioritise problems.





**Figure 1**  
The community action cycle

**Table 1: Content of first ten women's group meetings**

Stage in the cycle	Meeting	Content
Introduction	1	To introduce the group to MIRA Makwanpur's work
	2	To discuss why mothers and newborn infants die To introduce how MIRA will work in the community
Problem Identification	3	To find out how women understand maternal and neonatal problems
	4	To find out what kind of maternal and neonatal problems are in the community
	5	To discuss whether the maternal and neonatal problems are common To identify strategies to collect information from the community
Problem Prioritisation	6	To share the information collected from other women in the community To decide what are the three most important maternal and neonatal health problems
		To discuss possible strategies for addressing the prioritised problems
Planning together	7	To discuss which other community members should be involved in developing strategies
	8	To discuss how to prepare for the community members meeting
	9	The community members will learn about what the women have been doing
	10	The community members will learn about the three problems identified by the women The community members will learn about the possible strategies To reach a consensus of the strategies



**Figure 2**  
Women's group and facilitation manager

#### *Planning together*

The objective of these meetings was to encourage women to identify local and low cost ways of tackling the prioritised problems using local resources. Many examples were listed in the manual and the supervisor was encouraged to support the facilitator during these meetings. The idea behind these meetings was to enable the women to prepare a plan to tackle the problems they had found, which would then be presented to their community.

#### *The community meeting*

A community meeting was planned and organized by the groups to enable increased community participation and to legitimize the work of the group. The community was invited to hear what the women's group had been doing, and to participate in *planning together* strategies. Most groups decided that community leaders would be invited by letter, and other households would be verbally invited.

The groups also discussed the way they would present their findings and practised to develop their confidence.

The supervisor supported the local facilitator and the group, and played a key role in facilitating the meeting. After introducing MIRA and its role in the community, the women's group presented their prioritised problems and suggested strategies to tackle them.

#### *Methods of data collection and analysis*

Data were collected through a variety of qualitative techniques. Participant observation was carried out by the technical advisors to MIRA (NM and JM). They helped design and implement the intervention, and lived in the vicinity of the head office in Hetauda, Nepal, throughout the study period (JM succeeded NM). They visited the field many times and attended facilitation team meetings regularly. The advisors are of British nationality but have

an excellent spoken command of Nepali language and have a background in anthropology and sociology. Although they did not keep a diary as is usual in participant observation, their reflections and observations were noted in monthly reports and topic reports which have been used in this analysis. These reports were also contributed to and discussed with the facilitation team (facilitators, supervisors, and senior facilitation manager) who also added their reflections and observations. The technical advisor (JM) and senior facilitation manager (ST) analysed monthly reports and meeting minutes and reached consensus on themes emerging from the data, and issues of interest. Although there are limitations to this method of data analysis (the cultural background of the technical advisors and the fact that a diary was not kept), we wished to present the results of operational research that makes use of less formally recognized qualitative data collection techniques. Analysis of the data by more than one person strengthens the analysis and using different methods of data collection enables triangulation of the data.

### Results

Out of 111 women's groups, 77 moved on to develop and implement strategies and 100 groups continue to meet to discuss perinatal health. Particular reasons for which the remaining groups did not meet include the unstable security situation, lack of support from local leaders, husbands or health workers, and general lack of interest.

#### What makes an active women's group?

The continuing activity of most groups suggests that usually group members found the experience useful and enjoyable. Not surprisingly, the activity of the groups varied. We found no specific formula for an active women's group. Previous studies suggested that homogeneity of members was conducive to a successful group [20,21], but our groups showed much ethnic and social diversity. Issues of ethnicity, geography and distance from a market area did not uniformly affect the activity of groups. For example, there were two particularly active groups near market areas, but in other areas factors concurrent with living near a market – such as higher socioeconomic status and less cohesion between households – did not facilitate enthusiastic women's groups. Some groups were dominated by women from higher castes, but in others these higher castes served as a stimulant to more traditionally subservient or timid ethnic groups. Issues of local support from political groups, local health staff and men also seemed important. Other studies have also found that supportive husbands make it easier for women to participate in groups [22]. In most communities supervisors and facilitators had been successful in establishing good community rapport, and strategies were agreed to help maintain community support, such as facilitators attending

**Table 2: Problems prioritised by women's groups**

Neonatal Problems	Number of groups
Pneumonia in the newborn infant	31
Low birth weight	16
Jaundice in the newborn infant	12
Neonatal death	7
Breathing problem in the newborn infant	6
Infant not feeding	4
Green stool in the newborn infant	3
Wounds in the newborn infant	2
Tetanus in the newborn infant	1
Eye and ear infection in the newborn infant	1
<b>Maternal problems</b>	
Retained placenta	58
Vaginal Discharge	42
Malpresentation	30
Headache in the mother	22
Post partum haemorrhage	20
Fever (unspecified if in mother or baby)	15
Breast problems	13
Ante partum haemorrhage	11
Miscarriage	11
Abdominal pain in the mother	6
Oedema of hands and legs in the mother	6
Prolonged labour	5
Maternal death (delivery complications)	2
Anaemia in the mother	2
Vomiting in the mother	1
Missing data	3
<b>Total</b>	<b>330</b>

antenatal clinics and supervisors presenting reports to Village Development Committee chairpersons.

#### Problem prioritization

Women actively participated in learning together and gathered much information from their communities. The prioritized problems reflected local perceptions of the seriousness and frequency of specific problems and hence were different in each community (See Table 2).

#### Planning together

During the community planning meeting groups nominated members to present their findings and eight groups performed small socio-dramas. When local health personnel and area chairmen attended, discussions were livelier and planning more productive. Issues of health care underutilization by the community or issues of poor service delivery were often raised. In nine places, communities appeared apathetic towards the group and were not prepared to commit or participate in planning. In these



instances, they were happy for the group to plan and implement strategies and little discussion took place. In four places the group met with hostility from community leaders or health personnel or exceptionally low attendance from the community, usually due to local grievances with staff selection procedures or to the unstable security situation.

#### **Strategy development and implementation**

The strategies that were discussed during *planning together* and have been most successfully implemented were the mother and child health fund, locally produced clean home delivery kits, management and production of stretchers, and awareness raising through video shows.

#### **Mother and child health fund schemes**

69 groups favoured mother and child health funds as a way of overcoming the cost barriers to seeking and obtaining care. The cost of consultation, medicine and transport is a real reason that families do not gain access to services in Nepal [23]. MIRA provided training to fund management committee members elected from each group. These committees sometimes included literate community members not attending the group. Each group developed their own policy with regard to how money would be collected, who would be able to access it, how often it would be collected, and who would be responsible for managing it. 23 months after the first mother and child health fund was established, groups had generated between 731 rupees (10.5 US dollars) and 9635 rupees (133.8 US dollars).

#### **Clean home delivery kits**

The clean home delivery kit is advocated by the World Health Organisation as an effective way to promote cleanliness during home delivery and to reduce the risk of maternal and neonatal infection [24,25]. In Nepal, a local private company (MCH Products Pvt Ltd) has produced a clean home delivery kit, approved by the Ministry of Health, which contains a blade, a bar of soap, three cord ties, a plastic coin for cord cutting, a plastic sheet, and a set of pictorial instructions. There are problems with distribution to remote rural areas and other difficulties regarding local acceptability and price [26].

A few groups were keen to develop their own locally produced clean home delivery kit, and facilitators disseminated this idea to motivate other groups by example. 19 groups have made clean home delivery kits and four groups have reproduced subsequent batches. Groups have decided the price, but all groups sell at a lower price than the MCH products kit, with profits going into the mother and child health fund. The pictorial instruction leaflet was developed with a local artist and was piloted in the community. The groups have also

explored different selling points: local shops, Female Community Health Volunteers and Traditional Birth Attendants, and group members sold kits to their friends and neighbours. Recently, groups from one Village Development Committee have used free distribution of clean home delivery kits as an incentive to attend for antenatal care; the kits are free for women who attend at least four times.

#### **Stretchers**

In the study area, most births take place in the home [27] and transportation of women who encounter problems is difficult. Women's groups therefore identified the need for stretchers. 19 groups decided to raise money for stretchers themselves and the other 23 groups utilized local resources such as forest user groups or Village Development Committee offices. Women's groups investigated if there were any existing stretchers in their area, or if these needed repair. One group felt that the modern style of stretcher was not suitable for carrying women across difficult terrain, and therefore made a bamboo basket (*dhoko*) which is traditionally used to carry fodder or crops using a head strap (*tump line*). Some women's groups assumed management of unused stretchers, ensuring their accessibility and promoting their use, with 35 groups levying a fee for usage.

#### **Awareness raising through video shows**

During the community meetings, many groups felt that there was a lack of awareness about perinatal health problems and how to deal with them. MIRA had previously researched and produced a 20 minute film about newborn care in Makwanpur and the groups were keen to use it in their communities. Group members approached those households in the community with electricity and a television, and the video was shown in homes or public buildings. Although not all of the study area has electricity, the video was shown in 10 out of 12 Village Development Committee areas, attracting an audience of more than 2100.

#### **Participatory health education**

During the identification of strategies to address problems, there was a tendency to mismatch prioritized problems and strategies. For example, one group suggested tackling the problem of post-partum hemorrhage by attending antenatal care. Another group considered that the problem of vaginal discharge during pregnancy could be addressed by training new Traditional Birth Attendants. During the first ten meetings, and from previous data analyses, the team found an overwhelming preference for care within the community, in terms of place of birth and seeking solutions to health problems [16,27]. Home practices with unequivocal allopathic clinical benefit were rarely mentioned. There was also little knowledge about

what kind of problems could be managed at different health service institutions, and it appeared that communities define the "seriousness" of a problem in a different manner to the allopathic model.

Therefore, the team concluded that perinatal health education would be useful during the development of the strategies. It was felt important to avoid turning the facilitators into educators, and therefore a participatory form of health education was developed, based around a picture card game.

#### *The picture card game*

A packet of small hand held cards of different shapes was developed in order to address the mismatch between problems and strategies and to promote participatory learning. Each shape of card represents either a problem (circle shape), a prevention activity (triangle shape), a home-care activity (house shape), or a health institution (square shape). The cards are pictorial and were developed with the MIRA health team and a local artist (see Figures 3 and 4). They were extensively piloted with women's groups and adapted accordingly. A manual for facilitators was also developed to accompany the cards. The card game is played in the group by passing round the cards and discussing the pictures. The group members match problem cards to their corresponding prevention activities, home care activities or type of health institution that could treat that problem. The card game worked well in facilitating discussion, and women and facilitators both enjoyed the learning experience. The team completed a participatory evaluation of the game with a sample of groups which indicated that the game also facilitated learning about danger signs, home care and prevention activities. Group members are presently taking the picture cards on visits to pregnant women in the community who are not group members.

#### *Service quality spin-offs*

##### *Community health volunteers*

The facilitator has worked to involve and support female community health volunteers with their work in the community. 70 group meetings have regular attendance and active involvement of the local female community health volunteer and traditional birth attendant. The female community health volunteer is the lowest cadre of government appointed health staff and is responsible for one ward. She is unpaid and has a broad job description mainly focused around health education. In theory, she should run monthly women's group meetings to facilitate health education and discuss issues of maternal and newborn health. Although she receives initial and refresher training, she is often left to work unsupervised and unsupported, and in practice female community health volunteers find it difficult to run women's groups. By seeking

the participation of the female community health volunteer in the groups, we gave her a forum to conduct her work and increase her contact with her user group.

In twelve wards the women's group was invited by the local health institution to play an active role in selection of new female community health volunteers and traditional birth attendants. The group had created good links with the health institution, which could be exploited for future service quality improvements. Clearly, the health institution and the community consider many groups as legitimate entities with a role to play in the health of women and their children. It also appears that members of women's groups have become more involved with their local health services.

In one area women's group members responded to the needs of women visiting an outreach clinic for antenatal care and family planning. Women were complaining of a lack of privacy and there was no furniture in the clinic. The group contacted the local forest user group to supply materials for rudimentary furniture and collected money for the purchase of cloth for curtains. In several cases, the women's group was a medium for brokered links between health service providers and users.

#### *Proxies for empowerment effects?*

One group put a sign on the door of their meeting place indicating a sense of ownership. Ten out of 12 facilitators have been invited to participate in other meetings and community activities as their role as key actors in the community is being recognized and developed. Women's groups have sung the song from the video film at the annual women's festival, and a supervisor initiated discussion about newborn health in a local bus using a cassette of the song from the film. Another women's group organised a perinatal care quiz that was carried out with nearby women's groups and community members.

#### **Discussion**

We have described the development and implementation of a large scale participatory intervention with women's groups. This was adapted from a smaller scale project developed in Bolivia, and implemented in a poor rural population of 86 000 in Nepal. The effects on health outcomes, reported elsewhere, were dramatic.

During the process of developing and implementing the intervention we had to be flexible and respond to the needs of the group. Group members and the wider community clearly faced difficulties when thinking about ways to tackle perinatal problems. These difficulties raised issues around culture and our facilitation role.





**Figure 3**  
Women's group using picture cards

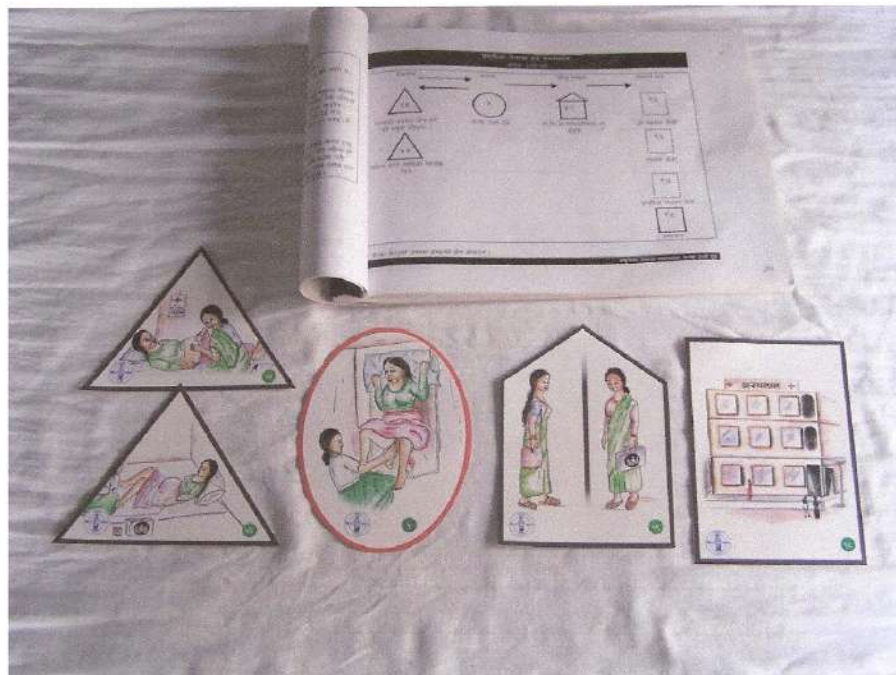
#### **Striking a balance between support and directiveness**

It is highly likely that the facilitation team's attempts to adequately support the facilitators may have led to less participatory processes taking place, especially in the case of strategy development. The facilitation manual was considered by the facilitation team as an essential resource. Examples were often given to enable facilitators to grasp key concepts before conducting a meeting. The manual was designed as a reference guide but evidently became more like an instruction booklet, as the strategies most commonly adopted during community meetings were those given as examples in the manual. The reasons behind this usage of the manual illustrate some of the key issues in implementing a participatory project. To truly facilitate, and not be directive, is a difficult technique to learn, especially in a hierarchical society where the facili-

tator's education has emphasised rote learning rather than independence of thought [28]. Our facilitators were also keen to educate and provide the answers, and it may have appeared easier (in the short term) to suggest things for groups to do than to facilitate open discussion. The self-confidence or ability of the facilitator to manage the chaos and unpredictability resulting from a truly participatory process was often lacking, although their facilitation skills developed with time.

#### **Power and culture**

Difficulties in linking problems to strategies may also be explained in part by the cultural phenomenon of fatalism, '*ke garne*' (what to do?). Bista described '*ke garne*' as a belief in fatalism which leads to the feeling that "one has no personal control over one's life circumstances, which are deter-



**Figure 4**  
Picture card game and manual

mined through a divine or powerful external agency" [29]. He argued that this fatalism and dependency affects the work ethic and achievement motivation in Nepal. Concepts of planning, orientation to the future, and sense of causality, are all affected. Our study experience was that fatalism affected both the way people viewed themselves in relation to a problem, and also the power and capacity they believed themselves to have in overcoming it.

**What has been the impact of the women's groups and their strategies?**

In cases where there was a mismatch between problem and strategy, or when groups developed strategies suggested by MIRA, we hope that these groups will benefit from the implementation process alone. The strategies in the manual are not necessarily evidence-based, and it may

be that the process of implementation is more beneficial than the strategy itself. Through implementation, interaction between the wider community and the group may be increased, knowledge about the group may spread, and more people may become interested and involved in issues of perinatal health. To enable a better understanding of the intervention process, evaluations using both qualitative and quantitative methodologies are underway. The impact of the women's group intervention was evaluated in a cluster randomized controlled trial which showed a 30% reduction in neonatal mortality rates and a reduction in maternal mortality rates in the first 30 months of the trial[11]. Qualitative analysis will explore perceptions and process indicators to assess how the intervention affected the study area and community stakeholders. Cost analysis of the intervention will enable estimates



of cost-effectiveness and sustainability to be made. A comparison of the socio-economic status of women's group members with non-group members will allow an estimate of the equitability of the intervention.

The Millennium Development Goals for reductions in maternal and neonatal mortality in developing countries are unlikely to be met by 2015. In populations where maternal and newborn mortality rates are highest, most deliveries occur at home. It is essential that Safer Motherhood and Newborn Care Programmes design interventions which reach out to the poorest groups in order to change care practices at home, and care seeking for illness or complications of childbirth. Our participatory work with women's groups provides a model for an intervention that can be scaled rapidly in even the poorest and most remote communities.

### Conclusion

A large scale participatory intervention to improve pregnancy outcomes in rural Nepal through 111 women's groups has been described. Although we have faced contextual, cultural and security problems, we believe that the participatory approach can be a powerful tool in unleashing the creative potential to solve perinatal health problems in communities. Such an approach may have lasting benefits, affecting behaviour in subsequent pregnancies.

### Competing interests

The author(s) declare that they have no competing interests.

### Contribution by authors

JM wrote the first draft of the paper and contributed to the study design and collection of field data. ST, and BS contributed to the study design, collection of field data and analysis, and criticised later drafts of the paper. NM and DO contributed to the study design and analysis, and criticised later drafts of the paper. MM and HS contributed to the design of the study and criticised drafts of the paper. DM and AC contributed to the design of the study and supervision of the field programme, and criticised drafts of the paper. JM and AC will act as guarantors for the paper.

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**Appendix 4 Publication - Morrison et al. Utilisation and management of  
maternal and child health funds in rural Nepal**



































**Appendix 5 Publication - Manandhar et al. Effect of a participatory  
intervention with women's groups on birth outcomes in Nepal: a cluster  
randomised controlled trial**

## Effect of a participatory intervention with women's groups on birth outcomes in Nepal: cluster-randomised controlled trial

Lancet 2004; 364: 970–79

See Comment page 924

Mother and Infant Research  
Activities (MIRA), PO Box 921,  
Kathmandu, Nepal

(Prof D S Manandhar FRCP,  
B P Shrestha MSc,  
K M Tumbahangphe MSc,  
S Tamang BSc, S Thapa MSc,  
D Shrestha BSc, R Thapa BSc;  
J R Shrestha MPH); International  
Perinatal Care Unit

(D Osrin MRCP, N Mesko MSc,  
J Morrison MSc, J Borghi MSc,  
Prof A M de L Costello FRCP) and  
Centre for Paediatric  
Epidemiology and Biostatistics

(A Wade PhD), Institute of Child  
Health, University College  
London, 30 Guilford Street  
London WC1N 1EH, UK;  
Institute of Development  
Studies, Falmer, Brighton BN1  
9RF, UK (H Standing PhD); and  
Nepal Administrative Staff  
College, Kathmandu, Nepal  
(M Manandhar PhD)

Correspondence to:  
Prof Anthony Costello  
ipu@ich.ucl.ac.uk

Dharma S Manandhar, David Osrin, Bhim Prasad Shrestha, Natasha Mesko, Joanna Morrison, Kirti Man Tumbahangphe, Suresh Tamang, Sushma Thapa, Deji Shrestha, Bidur Thapa, Jyoti Raj Shrestha, Angie Wade, Josephine Borghi, Hilary Standing, Madan Manandhar, Anthony M de L Costello, and members of the MIRA Makwanpur trial team

### Summary

**Background** Neonatal deaths in developing countries make the largest contribution to global mortality in children younger than 5 years. 90% of deliveries in the poorest quintile of households happen at home. We postulated that a community-based participatory intervention could significantly reduce neonatal mortality rates.

**Methods** We pair-matched 42 geopolitical clusters in Makwanpur district, Nepal, selected 12 pairs randomly, and randomly assigned one of each pair to intervention or control. In each intervention cluster (average population 7000), a female facilitator convened nine women's group meetings every month. The facilitator supported groups through an action-learning cycle in which they identified local perinatal problems and formulated strategies to address them. We monitored birth outcomes in a cohort of 28 931 women, of whom 8% joined the groups. The primary outcome was neonatal mortality rate. Other outcomes included stillbirths and maternal deaths, uptake of antenatal and delivery services, home care practices, infant morbidity, and health-care seeking. Analysis was by intention to treat. The study is registered as an International Standard Randomised Controlled Trial, number ISRCTN31137309.

**Findings** From 2001 to 2003, the neonatal mortality rate was 26.2 per 1000 (76 deaths per 2899 livebirths) in intervention clusters compared with 36.9 per 1000 (119 deaths per 3226 livebirths) in controls (adjusted odds ratio 0.70 [95% CI 0.53–0.94]). Stillbirth rates were similar in both groups. The maternal mortality ratio was 69 per 100 000 (two deaths per 2899 livebirths) in intervention clusters compared with 341 per 100 000 (11 deaths per 3226 livebirths) in control clusters (0.22 [0.05–0.90]). Women in intervention clusters were more likely to have antenatal care, institutional delivery, trained birth attendance, and hygienic care than were controls.

**Interpretation** Birth outcomes in a poor rural population improved greatly through a low cost, potentially sustainable and scalable, participatory intervention with women's groups.

### Introduction

Of the world's 4 million annual neonatal deaths, 98% occur in developing countries.<sup>1</sup> Infant and child mortality rates have declined, notably through better control of diarrhoea, pneumonia, and vaccine preventable disease, and the importance of the newborn period has increased. In India, neonatal mortality now accounts for up to 70% of infant mortality.<sup>2</sup> Most perinatal and neonatal deaths happen at home, and many could be avoided with changes in antenatal, delivery, and newborn care practices.<sup>3</sup> However, primary and secondary health-care systems have difficulties in reaching poor rural residents, and a potentially effective perinatal health strategy must recognise this reality. In Makwanpur district, Nepal, for example, 90% of women give birth at home, and trained attendance at delivery is uncommon.<sup>4</sup>

We are unaware of any randomised controlled trial of community based strategies to reduce neonatal mortality, a shortfall that indicates the absence of information on demand-side interventions.<sup>5</sup> Two studies have made important contributions in this area. Bolivia's Warmi

project—an uncontrolled before-and-after study—was implemented in a poor rural population of 15 000 people with little health-system infrastructure. The project worked with women's groups to encourage participatory planning for mother and infant care,<sup>6,8</sup> and showed a fall in perinatal mortality rate from 117 to 44 per 1000 births over 3 years. In India, the SFARCH group reported a non-randomised controlled study from a rural population of 80 000 in Gadchiroli, Maharashtra.<sup>7</sup> The intervention entailed training of traditional birth attendants, health education, and a new cadre of supervised village health workers who visited newborn infants at home, identified warning signs, and managed sepsis with antibiotics. After 3 years the neonatal mortality rate had fallen by 62%. Replication and scaling up of this exciting community-based model presents policy makers with some challenges, particularly because of the need for a new cadre of community health worker to deliver injectable antibiotics at home.

Community participation has long been advocated to build links between primary services and their users,<sup>10–12</sup> and to improve service quality.<sup>13–15</sup> However, the evidence



base for the effectiveness of participatory models is scarce.<sup>5,16</sup> Previously, we showed no effect of direct education by health workers on infant care practices and care-seeking behaviour after delivery.<sup>17</sup> In view of the Bolivian model, we thought that a participatory approach might have more effect on perinatal care practices and might increase consultation for difficulties in pregnancy and the newborn period. Although external facilitators of user groups have proven valuable in agriculture and forestry,<sup>18,19</sup> to our knowledge no study has rigorously assessed such a potentially scalable approach to improving reproductive health outcomes.

We postulated that a community-based participatory intervention could reduce the neonatal mortality rate from 60 to 40 per 1000 livebirths. The MIRA Makwanpur trial was a cluster-randomised controlled trial of such an intervention in a rural mountainous area of Nepal. The trial tested a large-scale intervention, using facilitators to work with women's groups in a population of 170 000 covering 1600 km<sup>2</sup>. A cluster design was chosen because the intervention was structured around communities rather than individuals.

## Methods

### Study location and population

With a population of more than 23 million and a gross national income of US\$240 per person,<sup>20</sup> Nepal is a poor country whose development challenges are exacerbated by its geography and unstable political situation. Life expectancy is 61 years. The total fertility rate is 4.4 children per woman in rural areas,<sup>21</sup> and the estimated maternal mortality ratio is 539 per 100 000 livebirths.<sup>22</sup> 57% of women cannot read.<sup>23</sup> The estimated infant mortality rate is 64 per 1000 livebirths, the neonatal mortality rate 39 per 1000 livebirths, and the perinatal mortality rate 47 per 1000 births.<sup>23</sup> In rural areas, 94% of babies are born at home,<sup>22</sup> and only 13% of births are attended by trained health workers.<sup>23</sup>

Makwanpur district lies in Nepal's central region where the middle hills join the plains. The population of about 400 000 subsists mainly on agriculture and the largest ethnic groups are Tamang and Brahmin-Chhetri. The district hospital in the municipality of Hetauda has facilities for antenatal care and delivery, although operative delivery was not available during the study period. There are 7852 people per hospital bed.<sup>24</sup> The district health system makes perinatal care available through a network of primary health centres, health posts, subhealth posts, and outreach clinics. Traditional birth attendants are available throughout the district, but their attendance at births is less common than in some other parts of south Asia.<sup>4</sup>

Nepal is administratively divided—in descending order of size—into development regions, zones, districts, village development committees, and wards. We chose the village development committee as the cluster unit of randomisation for the following reasons: it is a standard

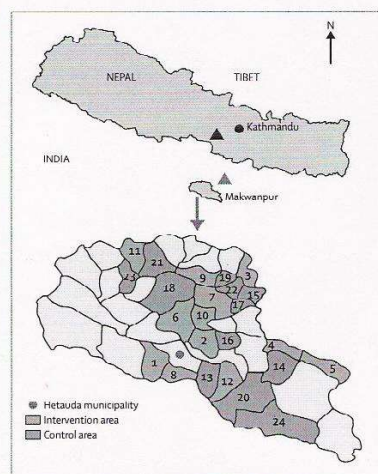


Figure 1: Makwanpur District, Nepal, and distribution of study village development committees

geopolitical unit, committee representatives were key points of liaison, and discussions with local people suggested that randomisation of smaller units would increase the risk of contamination. All 43 village development committees in Makwanpur district were eligible for randomisation, of which one was excluded at baseline for security reasons.

We enrolled a closed cohort of married women of reproductive age. Inclusion criteria were: consent given for involvement; age 15–49 years inclusive on June 15, 2000; married; and potential to become pregnant. Exclusion criteria included long-term separation from spouse and widowhood. Women who chose to participate in the study gave verbal consent and were free to decline to be interviewed at any time.

### Procedures

We matched 42 village development committees into 21 pairs. Because we did not have disaggregated neonatal mortality figures, pairing was based on a process of topographic stratification, grouping of village development committees with similar ethnic group distributions, and matching of pairs with similar population densities. We used a list of random numbers to select 12 pairs. These 24 village development committees formed the study clusters. We randomly allocated one cluster in each pair to either intervention or control on the basis of a coin toss (figure 1). Because of the



Figure 2: Typical women's group meeting  
Picture courtesy of Thomas Kelly and Save the Children, USA.

nature of the intervention the trial allocation was not masked, but analysis of primary and secondary outcomes was not done until just before the data monitoring committee meeting at 30 months. We generated the cluster allocation sequence in Kathmandu before enrolment of participants.

Enrolment activities were done from September, 1999, to November, 2000. A team of local enumerators mapped the 24 village development committees on foot, identified and allocated a unique identification number to every household (defined as a group of individuals sharing one kitchen), did a baseline census of demographic and socioeconomic indicators, and generated a list of female household members according to predefined written protocols. This document was scrutinised by a data auditor, a surveillance manager, and a group of local supervisors and converted into a list of women meeting the inclusion criteria for the cohort. From March, 2001, to July, 2001, a team of 44 field interviewers visited every potential member of the cohort, reassessed her for inclusion, explained the study, asked for her consent, allocated her a unique identification number, and completed an individual questionnaire, which included questions on demography, education, maternity history, details of any preceding pregnancy, home-care practices, and use of health services for perinatal illness.<sup>4</sup>

Surveillance began in February, 2001, and involved 28 931 participants in 28 376 households. The strategy we used was adapted from one used by the Nepal Nutrition Intervention Project, Sarlahi,<sup>25</sup> and has been described in detail elsewhere.<sup>26</sup> It entailed 255 ward enumerators, 25 field interviewers, and nine field coordinators. The local female enumerator visited all cohort members in the ward she was responsible for every month over the study period to record menstrual status. She recorded data on individualised printed forms. The nine ward

enumerators of every cluster met with a cluster interviewer once a week. In the absence of other explanatory circumstances, pregnancy was registered when a cohort member ceased menstruation for 3 months. The cluster interviewer did two interviews for every pregnancy: the first at 7 months of gestation, as near as possible to the transition between our definitions of miscarriage and stillbirth; and the second at 1 month postpartum, as near as possible to the transition between neonatal and infancy periods. In the event of an unfortunate outcome (miscarriage, maternal death, stillbirth, or neonatal death), the interview was done by a senior field coordinator. The interview was developed in Nepali and piloted and repiloted by the local team. It was modular to deal with different outcomes, covering antenatal, delivery and postpartum care, home care practices, maternal morbidity, neonatal morbidity, health service usage, and cause of death in the event of mortality.

In the event of neonatal death, we used an approach refined and locally adapted from existing questionnaires to establish cause of death. An open question about the cause of death was followed by a modular series of closed questions. The answers to these questions were designed to produce a classification of 14 causes of neonatal death based on those used by SEARCH in India,<sup>9</sup> and were classified by a paediatrician (DO) on

Phase	Meeting	Aim
Introduction	1	To introduce the study to the group
	2	To discuss why mothers and newborn infants die and how the intervention will work in the community
Problem identification	3	To ascertain how women understand maternal and neonatal problems
	4	To find out about maternal and neonatal problems in the community
	5	To understand the frequency of maternal and neonatal problems and to identify strategies to obtain information in the community
Problem prioritisation	6	To share information from other women in the community and to prioritise three important maternal and neonatal health problems
Planning together	7	To discuss possible strategies for addressing the priority problems
	8	To discuss involvement of other community members in developing strategies
	9	To discuss preparation for a meeting of community members
	10	To hold a meeting involving other community members to discuss the activities of the women's groups, the priority problems identified by the groups, and possible strategies, and reach consensus

Table 1: First ten women's group meetings



the basis of open text responses, modular closed questions, and a computer algorithm.

The average population per cluster was about 7000, spread over an area of 60 km<sup>2</sup>. For every intervention cluster we recruited one local female facilitator. Shortlists for this role were derived from nomination by community leaders, advertisement, and word of mouth, after which all potential candidates were interviewed. A cluster consisted of nine wards. The facilitator—a literate locally resident woman—convened one women's group meeting a month in every ward (figure 2). Some groups set up by local female community health volunteers already existed but their activity was sporadic. The role of the facilitator was to activate and strengthen groups and support them through an action research cycle.

The intervention needed a facilitator rather than a teacher, with abilities and training in participatory communication techniques. She needed to have a grasp of perinatal health issues and some knowledge of potential interventions so she could act as a broker of information and a catalyst for change. Although it was important that none of the facilitators had a health background, we gave them brief training in perinatal health issues. Supervision, and a manual based on the Warmi project methodology,<sup>27</sup> was integral to facilitator training and support. One supervisor provided support for every three facilitators by attending group meetings and making regular community visits.

The first step of the intervention was to discuss issues around childbirth and care behaviours in the community, which allowed facilitators to develop participatory learning skills and generated information on pregnancy and childbirth, covering beliefs and practices in both uncomplicated and complicated pregnancies.<sup>27,28</sup> The facilitators then supported the women's groups through monthly meetings (table 1). This phase of ten meetings lasted almost a year. In the next steps of the intervention, the women's groups implemented and assessed their strategies. One result of the process was that women sought more information about perinatal health. This information was provided through the iterative design and playing of a picture card game that addressed prevention, treatment, and consultation for typical problems in mothers and babies.

The form and content of discussions within women's groups varied, as did levels of involvement and potential strategies. Some typical strategies were community-generated funds for maternal or infant care, stretcher schemes, production and distribution of clean delivery kits, home visits by group members to newly pregnant mothers, and awareness raising with a locally made film to create a forum for discussion. Throughout the process the groups were involved in other health-related activities in their communities.

A baseline service audit identified weaknesses in the provision of antenatal, delivery, and newborn care in Makwanpur district. Because we aimed to test solely the

effects of the women's group intervention, health-service strengthening activities were undertaken in both intervention and control areas. We decided to do this process on ethical grounds because we hoped that it would benefit control areas<sup>29</sup> and on theoretical grounds because we thought that a degree of improvement in services would be necessary for the success of the trial intervention. We therefore ensured that primary health centres in the study area were equipped with locally made resuscitaires (open incubators that allow access to newborn babies while keeping them warm), phototherapy units, warm cots, and neonatal resuscitation equipment. We remedied some shortfalls in essential neonatal drugs once only and discussed strategies for resupply with local health-service managers. In partnership with the District Public Health Office, we organised training in essential newborn care for all cadres of government health staff and for female community health volunteers and traditional birth attendants. Community-based workers received a basic newborn care kit containing a rubber bulb for suction, tube-and-mask for assisted respiration, iodine, gauze, a baby wrapping cloth, and a pictorial manual.

We postulated that the women's group activities might lead to reductions in neonatal mortality rates in intervention clusters compared with control clusters. At the outset, we did not think perinatal mortality rates would be affected much, since we did not envisage that changes in home-care practices would lead to reductions in stillbirth rates.

The primary outcome was neonatal mortality rate (deaths in the first 28 days per 1000 livebirths). Prospective interviews undertaken through the surveillance system provided information on several other outcomes, including stillbirths and maternal deaths, uptake of antenatal and delivery services, home-care practices at delivery and postpartum, infant morbidity, and health-care seeking. We obtained background demographic and socioeconomic information to investigate cluster comparability.

Surveillance coordinators observed 10% of interviews and reviewed all questionnaires at nodal points in the field before transmitting them for review by data auditors. After audit and correction, sometimes needing transfer back to the site of collection, data were double-entered into a relational database management system in Microsoft SQL Server 7.0 (Microsoft Corporation, Redmond, WA, USA). The system further addressed data quality through predefined acceptability constraints.

We defined miscarriage as cessation of a presumptive pregnancy before 28 weeks of gestation and stillbirth as fetal death after 28 weeks of gestation but before delivery of the baby's head, which was a modification of the 22-week definition to meet local practicalities. We classified neonatal death as death of a liveborn infant within 28 completed days of birth. Early neonatal deaths refer to deaths within 7 completed

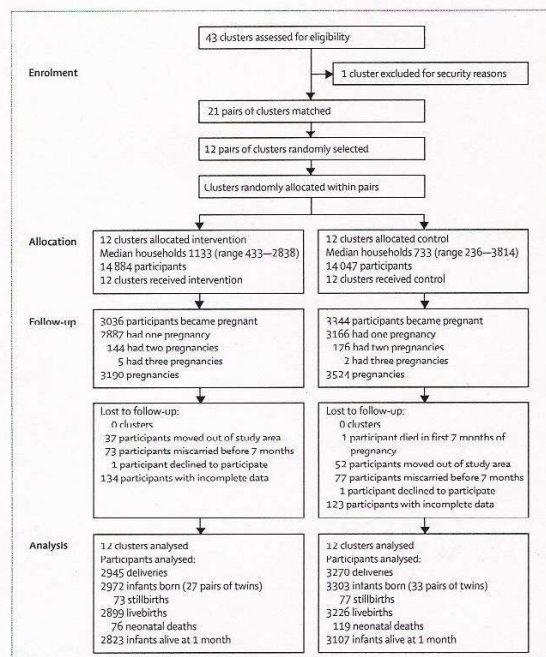


Figure 3: Trial profile

days and late neonatal deaths from 7 to 28 completed days of birth. Perinatal death describes either a stillbirth or an early neonatal death.

The study was approved by the Nepal Health Research Council and the ethics committee of the Institute of Child Health and Great Ormond Street Hospital for Children, and was done in collaboration with His Majesty's Government Ministry of Health, Nepal. We discussed the aims and design of the trial at a national meeting in 1998. After this time, we held a series of meetings with members of the Makwanpur District Development Committee, the Chief District Officer, and local stakeholders. In early 2000, the chairpersons of the 24 village development committees involved in the study gave signed consent on behalf of their communities.

Benefits to the control clusters were improvements in equipment and training provided at all levels of the health-care system. All community-based members of the study

team were recruited locally and undertook their activities in their home areas. When the study surveillance team noted minor illness in mothers or infants, they encouraged attendance at an appropriate health facility. In the event of severe illness, team members had an ethical responsibility to assist with rapid and appropriate transport and treatment, irrespective of allocation. All information provided by participants remained confidential. Access to information was restricted to interviewers, supervisors, data auditors, and officers, and research staff at the analytical level. No analyses or outputs included the names of participants.

#### Statistical analysis

To determine the number of cluster pairs to be enrolled, we had to estimate the coefficient of variation in outcome between clusters within matched pairs ( $k_c$ ) and the expected number of births per cluster over the timescale of the study. Based on national and district estimates, we assumed a neonatal mortality rate of 60 per 1000 livebirths, an average of 480 births per cluster, and a  $k_c$  value in the range 0.15–0.3. We estimated that inclusion of 12 pairs of clusters would allow us to detect a reduction in neonatal mortality of between 27% and 38% (37–44 per 1000 livebirths) with 80% power at a 5% significance level.<sup>30</sup> The corresponding estimates of intraclass correlation are between 0.0055 and 0.0061. Because we did not envisage any adverse effects of the intervention at either cluster or participant level we did not use any stopping rules. After the first year of surveillance, we saw that birth rates were lower than expected on the basis of estimates. The trial steering group decided not to assess neonatal mortality rates until we had obtained data for 2 complete years of births from introduction of the intervention. We therefore undertook a preliminary analysis in November, 2003, and presented the findings to an independent data monitoring committee. The committee considered issues of quality, confidentiality, and analysis and recommended definitive analysis and publication of the 2-year findings.

The analysis was undertaken as intention to treat at both cluster and participant levels. Participants who had begun the trial as residents of a given cluster were retained as residents even if they had moved to another cluster during the trial period.

Within the prospective cohort, we compared neonatal mortality rates, stillbirth rates, and maternal mortality ratios between control and intervention groups, taking account of clustering and the paired nature of the data, with hierarchical logistic models (Mlwin version 1.1). We estimated intraclass correlation coefficients from retrospective neonatal mortality and stillbirth data by analysis of variance within Stata version 8. Secondary outcomes and process indicators were compared with adjustment for clustering. All estimates are presented with 95% CIs. This study is registered as



International Standard Randomised Controlled Trial, number ISRCTN31137309.

#### Role of the funding source

Representatives of the UK Department for International Development (DFID) suggested that no health-care activities should be carried out in parallel with existing government services and that—for sustainability reasons—no funding should be available for women's group activities. Apart from these issues, the sponsors of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

#### Results

Figure 3 shows the trial profile. All 24 clusters selected for inclusion received their allocated intervention. Between Nov 1, 2001, and Oct 31, 2003, 3190 pregnancies happened in intervention clusters and 3524 in controls. Presumptive miscarriage rates were 2.3% (73/3190) in intervention clusters and 2.2% (77/3524) in control clusters. Loss to pregnancy follow-up as a result of migration, withdrawal of consent, or incompleteness of surveillance data was 5.4% (172/3190) in intervention clusters and 5.0% (176/3524) in control clusters. 2972 births (including 54 twins) were available for analysis in intervention clusters and 3303 (including 66 twins) in control clusters.

Table 2 presents baseline characteristics of intervention and control clusters. Although the median number of households per cluster was lower in control clusters, the total numbers of households and participants who became pregnant were similar. Some evidence exists of less poverty in intervention than control clusters: household asset scores and participant schooling—but not recalled annual food sufficiency—seem to slightly favour the pooled intervention clusters. The age breakdown does not suggest differences between intervention and control clusters, either for population structure or for participants who became pregnant.

For estimated baseline mortality rates, participants in intervention clusters recalled 11 415 livebirths and 290 neonatal deaths in the 5 years preceding our census (neonatal mortality rate 25.4 per 1000 livebirths). Participants in control clusters recalled 12 132 livebirths and 304 neonatal deaths (neonatal mortality rate 25.1 per 1000 livebirths). Cluster-specific breakdown of these pooled data showed that neonatal mortality rates were higher in intervention than control clusters in four pairs, similar in four pairs, and higher in control than intervention clusters in four pairs. Although valid for cluster comparison, the prospective findings in the same population suggest that maternity histories substantially underestimated actual neonatal mortality rates.

	Intervention clusters	Control clusters	Pregnancies in intervention clusters	Pregnancies in control clusters
Number of households	148 (9)	1349 (7)	2923	3189
Median per cluster (range)	1133 (433–2838)	733 (236–3814)	207 (158–451)	248 (59–796)
Number of participants	14884	14047	3036	3344
Median per cluster (range)	1110 (487–2824)	777 (219–4069)	214 (164–463)	264 (61–835)
Household asset score	13532	12170	3036	3344
None of the assets on the list	6122 (45%)	6223 (51%)	1545 (51%)	1866 (56%)
Clock, radio, iron, or bicycle	4094 (30%)	4476 (37%)	954 (31%)	1171 (35%)
More costly appliances	3316 (25%)	1461 (12%)	537 (18%)	307 (9%)
Household food sufficiency	13532	12170	3036	3344
Less than 8 months annually	4090 (30%)	3372 (28%)	972 (32%)	1002 (30%)
Participant age	13532	12170	3036	3344
Younger than 20 years	1130 (8%)	973 (8%)	719 (24%)	721 (22%)
20–29 years	5102 (38%)	4758 (39%)	1696 (56%)	1804 (54%)
30–39 years	4265 (32%)	3782 (31%)	556 (18%)	704 (21%)
40 years or older	2945 (22%)	2657 (22%)	65 (2%)	105 (3%)
Participant schooling	13532	12170	2893	3141
None	11031 (82%)	10741 (88%)	2122 (73%)	2681 (85%)
Primary	1562 (12%)	957 (8%)	503 (17%)	307 (10%)
Secondary or higher	939 (7%)	472 (4%)	268 (9%)	153 (5%)
Participant could not read	8981 (66%)	9664 (79%)	1734 (56%)	2418 (72%)

Table 2: Baseline characteristics of intervention and control clusters and pregnancies in intervention and control areas

Figure 4 shows within-cluster neonatal mortality rates for each of the 12 cluster pairs. The line of equality has been superimposed on this graph. In 11 cluster pairs, neonatal mortality rates were lower in the intervention group. The pooled rate in the intervention group was nearly 30% lower than in the control group (table 3). Hierarchical modelling—taking clustering into account—yielded an odds ratio of 0.70 (95% CI 0.53–0.94) for neonatal mortality in the intervention clusters compared with the control clusters. The intraclass correlation coefficient estimated from retrospective data was 0.00644 (95% CI 0.00004–0.0128).

Stillbirth rates did not differ between intervention and control clusters (table 3). The intraclass correlation coefficient estimated from the retrospective data was

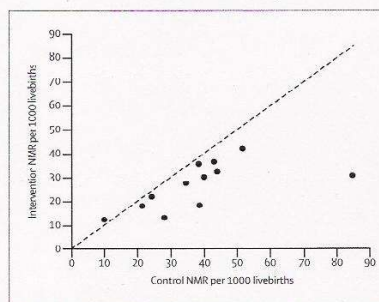


Figure 4: Neonatal mortality rates in intervention and control areas  
NMR=neonatal mortality rate.

	Intervention clusters	Control clusters	Adjusted odds ratio (95% CI)
<b>Documented births</b>	2972	3303	
Livebirths	2899	3226	
Stillbirths	73	77	
<b>Neonatal deaths</b>	76	119	
Early (0-6 days)	50	70	
Late (7-28 days)	26	49	
<b>Maternal deaths</b>	2	11	
Stillbirth rate per 1000 births	24.6	23.3	1.06 (0.76-1.47)
Neonatal mortality rate per 1000 livebirths	26.2	36.9	0.70 (0.53-0.94)
Maternal mortality ratio per 100 000 livebirths	69	141	0.22 (0.05-0.90)

Table 3: Mortality rate comparisons between intervention and control clusters

0.00438 (95% CI 0.0-0.00948) for the stillbirth rate. With limited sample size, maternal mortality was not a predefined outcome of the study. The maternal mortality ratio was about 80% lower with intervention than with control clusters (adjusted odds ratio 0.22 [95% CI 0.05-0.90]).

Table 4 presents process indicator outcomes. In general, they suggest so called healthier behaviours in intervention clusters: women in these clusters were more likely than those in the control clusters to have had antenatal care, to have taken haematinic supplements, to have given birth in a health facility, with a trained attendant or a government health worker, to have used a clean home delivery kit or a boiled blade to cut the umbilical cord, and for the birth attendant to have washed her hands. No differences were noted in delayed

wrapping of newborn infants, early bathing, or breastfeeding. Rates of maternal morbidity were similar, but women in intervention clusters were more likely than those in control clusters to have visited a health facility in the event of illness. Likewise, infant illness was more likely to have led to a visit to a health facility.

The most usual causes of neonatal death were complications of preterm birth, presumptive birth asphyxia, and infection. The pattern of causes did not differ between groups, but we noted that infection-related deaths were less frequent in intervention clusters.

## Discussion

We have shown that an intervention in rural Nepal, entailing women's groups convened by a local woman facilitator, reduced neonatal mortality by 30%. Maternal mortality, although not a primary outcome of the trial, was also significantly lower in intervention areas. The intervention seemed to bring about changes in home-care practices and health-care seeking for both neonatal and maternal morbidity. The activities of one facilitator in a population of 7000 rapidly reached a high proportion of pregnant women, even in poor and remote communities. Only 8% of married women of reproductive age ever attended a group, but the groups attracted 37% of newly pregnant women, and members raised awareness of perinatal issues outside the groups themselves.

Cluster-randomised trials are susceptible to bias. The intervention and control areas had similar retrospective neonatal mortality rates, but some differences were noted in literacy and poverty indicators. We do not think these factors could account for the noted differences in mortality rates, but they do merit further investigation. Surveillance methods could have affected outcomes, although this activity would have taken place in both intervention and control areas.

Two potential effect modifiers were the convening of women's groups in collaboration with government-trained female community health volunteers and health-system strengthening activities across intervention and control areas. Would work with women's groups have the same degree of effect in areas where no community health volunteer was present or no training of health workers in essential newborn care took place?

Security problems in the district escalated during the third year of the study. Supervisory activities were intermittently compromised in four clusters (two intervention and two control), and although no women's group was disbanded, four groups had to postpone their meetings several times.

The intervention seemed to be acceptable: 95% of groups remained active at the end of the trial despite no financial incentives and the opportunity costs incurred by women spending time away from other tasks. With appropriate investment and political commitment, we think the intervention could be scaled up rapidly. Scaling-

	Intervention clusters	Control clusters	Adjusted odds ratio (95% CI)
<b>Pregnancies</b>	3190	3524	
Any antenatal care	1747 (55%)	1051 (30%)	2.82 (1.41-5.62)
Any iron and folic acid supplements	1574 (49%)	1152 (27%)	1.99 (1.14-3.46)
Any perceived maternal illness from 7 months gestation to 1 month postpartum	668 (21%)	916 (26%)	0.74 (0.43-1.28)
Visited health facility in event of illness	333 (50%)	207 (22%)	3.37 (1.78-6.37)
<b>Deliveries</b>	2945	3270	
Institutional deliveries	201 (7%)	66 (2%)	3.55 (1.56-8.05)
Birth attended by government health provider	272 (9%)	102 (3%)	3.12 (1.62-6.03)
Specifically, doctor, nurse, or midwife	207 (7%)	69 (2%)	3.53 (1.54-8.10)
Birth attended by traditional birth attendant	199 (7%)	129 (4%)	1.70 (0.93-3.11)
Used a clean home delivery kit	550 (19%)	154 (5%)	4.59 (2.83-7.45)
Used a boiled blade to cut the cord	1580 (54%)	827 (26%)	3.47 (1.39-8.69)
Attendant washed her hands	1988 (68%)	1064 (33%)	5.5 (2.40-12.6)
<b>Livebirths</b>	2899	3276	
Cord undressed or dressed with antiseptic	2356 (81%)	2340 (73%)	1.62 (0.58-4.55)
Baby wrapped within 30 min	1975 (68%)	2257 (70%)	0.92 (0.37-2.31)
Baby bathed within 1 h	2880 (99%)	3207 (99%)	1.11 (0.46-2.71)
<b>Infants alive at 1 month</b>	2823	3107	
Any of three infant illnesses (cough, fever, diarrhoea)	919 (33%)	1320 (42%)	0.65 (0.36-1.20)
Taken to health facility in event of illness	219 (24%)	131 (10%)	2.84 (1.65-4.88)
<b>Breastfed infants</b>	2864	3181	
Initiated within 1 h	1780 (62%)	1718 (54%)	1.40 (0.52-3.79)
Discarded colostrum	820 (29%)	1344 (42%)	0.55 (0.27-1.10)

Table 4: Process indicator outcomes



up could be achieved through both government and non-government organisations and would not necessarily need to be managed by health-sector personnel, although coordination might be essential. Local rather than central government might be preferable to lead the process for reasons of participation, accountability, and sustainability.

A cost effectiveness analysis was done alongside the study. The cost per newborn life saved was US\$3442 (\$4397 including health-service strengthening costs) and per life year saved \$111 (\$142 including health-service strengthening costs). This value compares favourably with the World Bank's recommendations that interventions less than US\$127 per disability-adjusted life year saved are some of the most cost effective.<sup>31</sup> Our estimates probably underestimate the programme's cost-effectiveness. They do not include benefits to infants born outside the closed cohort surveillance; they ignore longer-term benefits of the intervention to subsequent pregnancies; they exclude benefits to infants of reduced morbidity and to mothers from reduced morbidity and mortality; and they omit potential savings in set up and supervision costs if the activities were replicated elsewhere.

Two key elements distinguished our approach from conventional health education. First, women's groups looked at demand-side and supply-side issues. Second, the approach emphasised participatory learning rather than instruction. The women's group strategies—the picture card game, health funds, stretcher schemes, production and distribution of clean delivery kits, and home visits—also entailed interaction outside the groups, which increased awareness of perinatal issues.

The renewed interest in community participation in health care<sup>32</sup> is attributable partly to the scarcity of resources committed to primary care and partly to the perceived failure of conventional health education and primary health care to deliver substantial health benefits.<sup>33,34</sup> A major challenge has been to engage users and enable them to adopt positive health care behaviours. In many countries, local health committees have had little accountability to their communities, and the level of representation of beneficiaries such as women is low.<sup>35,36</sup> Beneficiaries themselves can be passive in the face of service bureaucracies<sup>37–39</sup> because of an absence of local ownership, different perceptions of priorities, and capture of resources by powerful groups.

If participation is a key element of primary health care then few controlled studies have been done of its effect on health outcomes. Participation is typically seen as an adjunct to implementation rather than as a primary intervention, and the distinction between a didactic approach to health education at community level and a participatory approach to developing strategies is blurred. For example, community-based health promoters have increased exclusive breastfeeding rates in Mexico<sup>40</sup> and India,<sup>41</sup> where diarrhoeal morbidity was also diminished. In Ethiopia, a randomised controlled trial of mother coordinators trained to teach other local

mothers to recognise symptoms of malaria in their children and to promptly give chloroquine achieved a 40% reduction in under five mortality.<sup>42</sup>

The procedure used to establish cause of death suggested that infection accounted for fewer deaths in intervention than control clusters. This finding lends support to the noted rises in antenatal care, trained birth attendance, clean delivery kit use, hand washing by birth attendants, and care seeking in the event of neonatal morbidity. These data complement the work of SEARCH,<sup>9</sup> whose intervention consisted of a package of activities. Scaling up the use of injectable antibiotics by community health workers presents difficulties for policy makers, and our less intensive intervention achieved half the SEARCH mortality reduction.

The effect of the intervention on maternal mortality was surprising in view of the size and power of the study and obviously needs replication. If validated, the finding would be noteworthy for the potential of this approach to achieve Millennium Development Goals.<sup>43</sup> The participatory strategy could benefit other health outcomes such as stillbirths, infant and childhood mortality, and malaria and HIV infection in pregnancy. The absence of effect on stillbirth rates shown in this trial does not rule out future success if issues such as nutrition received greater emphasis in women's groups.<sup>44</sup>

The trial findings raise several issues that we intend to address in subsequent work: differential changes in care practices between group members and non-members, the process of diffusion of behaviour changes within the population, an examination of potential confounding within the cluster-randomised design, further analysis and refinement of the verbal autopsies, and a detailed discussion of cost-effectiveness.

Progress towards the Millennium Development Goals for maternal and child mortality reduction has faltered. Our findings suggest that a demand-side intervention can achieve great reductions in neonatal and maternal mortality in poor and remote communities. The approach—a local woman facilitating women's groups—is potentially acceptable, scalable, sustainable, and cost effective as a public-health intervention. Assessment of demand-side interventions needs greater attention in primary care.<sup>9</sup> Studies are needed to assess how we can replicate the approach in different settings, as are large trials to examine effects on maternal morbidity and mortality.

#### Contributors

All authors contributed to the design of the study and criticised drafts of the paper. D S Manandhar and A M de L Costello were responsible for the conception and overall supervision of the trial. B P Shrestha managed the project under initial guidance from J K Shrestha. K M Tumbahangphe, S Tamang, S Thapa, D Shrestha, and B Thapa managed data collection, field intervention, health service activities, data entry and administration, respectively. N Mesko and J Morrison were technical advisors on intervention and qualitative aspects of the study, and D Osrin on quantitative aspects. J Borghi conducted the economic analysis with help from B Thapa. M Manandhar and H Standing advised on the facilitation process. D Osrin and A Wade carried out the

quantitative analysis. A M de L Costello and D Osrin wrote the first draft of the paper and were responsible for subsequent collation of inputs and redrafting.

#### Conflict of interest statement

We declare that we have no conflict of interest.

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## **Appendix 6 Training for qualitative data collection**

### **Aims and Objectives**

- To increase and/or develop the capacity of participants to collect qualitative data in a rigorous way.
- To give researchers experience of using focus groups, semi structured interviews and structured observations.

### **At the end of this training researchers will:**

- Be familiar with the main principles of qualitative research
- Be familiar with my study
- Be able to use open questions and understand their usefulness in qualitative research
- Know how to prepare for qualitative research in the field
- Know how to approach participants and arrange interviews and focus group discussions.
- Feel confident and able to conduct focus group discussions, semi structured interviews and semi structured observation.
- 

### **Training overview**

- Introduction, discussion of aims and objectives and structure of the training
- What is qualitative research?
- How is qualitative research different from quantitative research?
- The role of the researcher in qualitative research  
Exercise
- How to ask a question when collecting data  
Exercise
- Introduction to my study
- Who are my stakeholders and how did I choose them?
- Doing interviews in qualitative research  
Exercise  
Review interview checklist
- What are focus group discussions?
- The role of the observer
- Why do we use focus group discussions?
- What aspects influence a focus group discussion?  
Exercise
- What are common problems during focus group discussions?
- What can we do to have a successful focus group discussion?  
Review checklist
- What is observation?  
Exercise

## **Appendix 7 Topic guide for focus group discussion with women's group**

### **members**

Important points to say in introduction

- We want to learn from you about the community you live.
- We want to learn from you about your experience of MIRA.
- There are no wrong answers.
- We are doing this research to help MIRA evaluate their programme, so that other organisations working with communities can also learn how to do better.
- You can choose not to participate, and can stop the discussion or ask questions.
- Whatever you say is confidential, even MIRA facilitation team will not be told.
- Mongala is going to take some notes throughout the discussion

I would like to tape record the discussion because I want to remember all of the things that you say. This tape recording will be confidential and destroyed after we have used it. Is that ok?

**Topic 1 First I would like to ask you about the place that you live in. I am new to this place (I am from Kathmandu), so it would help a lot if you could tell me about what it is like to live here.**

What do you normally do in a day?

What do you and your family spend most of the time doing here?

What do you like about living here?

Why do you like this?

What do you not like about living here?

Why do you not like this?

When you have a problem in your ward, how is it solved?

Can you tell me about an example in this ward?

In what ways to women in this community help each other?

**Topic 2 Now I would like to ask you some questions about health.**

What kinds of health problems do people have here?

Where do you go and what do you do when you or your family get ill?

What else do you do?

What do other people do here when they get ill?

What do you think of the health facilities here? Tell me about an example.

**Topic 3 Now I would like to ask some questions about your own experience with the MIRA mother's group.**

How long have each of you been going to the meetings?

What have you been doing at the meetings? What happens at the meetings?

What do you like about the mothers group meetings?

What do you not like?

Since going to the meetings what do you do differently?

Why do you do this differently?

How do your friends and family feel about you going to the meeting?

Can you describe the facilitator? What is she good at? What is she not so good at?

**Lastly: From this discussion I have heard that...**

**Is that right?**

**Is there anything else you would like to say, or any question you would like to ask?**

**Thank you very much for your time.**

**Appendix 8 Topic guide for focus group discussion with Health  
volunteers in second phase of data collection (control area)**

**Important points to say in introduction**

- We want to learn from you about the community you live.
- There are no wrong answers.
- We are doing this research to help MIRA evaluate their programme, so that other organisations working with communities can also learn how to do better. We have asked people in other places about their community and about the way that NGOs/organisations work, and we would like to find out about your community from you.
- You can choose not to participate, and can stop the discussion or ask questions.
- Whatever you say is confidential
- Mangala is going to take some notes throughout the discussion

I would like to tape record the discussion because I want to remember all of the things that you say. This tape recording will be confidential and destroyed after we have used it.

Is that ok?

**First I would like to ask you about the place that you live in.**

Can you describe what it is like to live here? How do you and your family spend your time? (I am from Kathmandu and don't know what it is like to live here)

What do you like?

What do you not like?

How do you get new knowledge?

How do you hear about new things?

**I would like to ask you some questions about health and illness.**

What do other people here do when they get ill?

What do people think of the health services here?

What do you find difficult about your job? (what kind of problems do you experience in providing care to people in this VDC?)

**I would like to ask you about non governmental organisations.**

Can you describe any group activities or non governmental organisations that work here?

How do you feel about the way they work? What is good about them? What is bad?

What kind of impact have they made on this area?

What makes one NGO better than another?

What is the role of NGOs here?

**I would like to ask you about MIRA**

Have you heard of MIRA? What do they do?

What effect have MIRA had on your work?

What effect do you think they have had on your community?

MIRA has been working with women's groups in many other VDCs, and the number of newborn babies dying has reduced by a large amount. Why do you think that is?

**Lastly:**

**From this discussion I have heard that...**

**Is that right?**

**Is there anything else you would like to say, or any question you would like to ask?**

**Thank you very much for your time.**

## **Appendix 9 Themes generated by an independent researcher**

Lack of education

Traditional beliefs – shaman (spirits), making promises, exorcism

Christian beliefs

Belief in science – lack of belief in shamans

Syncretism – mixed beliefs (for example shaman and hospital)

Changes in health practices - reduction in pregnancy related problems, changes in shaman's practices, and changes in birthing practices

Feelings/emotions - responsibility, satisfaction, anger, happiness, irritation, boredom, security

Problems – lack of support, with money, current political situation, perception of lack of gratitude, age related difficulties, water

Health problems – of children/babies, of adults, with home deliveries – guesswork, lack of trained attendants

Needs – education – desire to learn, financial support, other support, better training,

Increased community knowledge

Community problem solving strategies

Importance of caste

Feelings/opinions about MIRA – satisfaction, dissatisfaction, lack of knowledge about MIRA, MIRA lack sensitivity



## **Appendix 10 Feedback of thematic analysis**

### **Feedback of results**

We conducted discussions with lots of different people in 2 wards of 2 different VDCs in Makwanpur last year. We were having these discussions to evaluate the work of MIRA and find out about the places in which MIRA works. We have listened to everything that everyone said, and we have summarised the opinions of people. We would like to hear from you if you think we have made the right summary. If you think that we have not mentioned anything that is important, or you think we have said something, which is not true, we would like you to tell us.

#### **Topic 1 Plurality**

We heard that some people in Makwanpur believe in the curative power of traditional healers (dhamis) and of medicine, and because of this belief, when you and your families get ill you call a dhama and you go to the hospital or medicine shop. The reasons for choosing a kind of care depend on different things. They depend on the cause of the illness, the kind of quality of care you think you will receive (including its curative capacity) and the distance that you have to go (who advice is taken from/who is the decision maker also?). We heard it was ok to hold views like this.

What do you think about this?

#### **Topic 2 Trust**

We heard that some people in Makwanpur sometimes have a lack of trust in the local health services (the health posts and TBA FCHV) and do not feel they receive a good quality of care there. People sometimes do not trust the medicine of the health post, and they do not trust the knowledge and practical skills of the health personnel.

We heard that NGOs are not always to be trusted. NGOs do not always work honestly in the villages.

What do you think about this?

#### **Topic 3 Learning and development**

We heard that people in Makwanpur think that going to groups is a good opportunity to learn. People think that NGOs and groups have enabled people to learn new things and 'move forward'. There are some people who do not understand the value of going to a group, and these are the people who are resistant to moving forward (to change) and they always talk about the times before.

We heard that MIRA mothers groups are viewed positively by those who 'understand' and viewed as threatening by those who do not 'understand'. The groups give the opportunity to learn new knowledge.

What do you think about this?

#### **Topic 4 Expectation**

We heard that people in Makwanpur have low expectation that the government will provide services for them. People expect NGOs to provide services and money and opportunities for learning. NGOs usually do provide money and services and

opportunities for learning in Makwanpur. People are disappointed when nothing visible (*replace with better Nepali word*) is given by an NGO. Although people like MIRA for giving knowledge, MIRA is criticised for not giving anything visible. People expect MIRA to give something.

What do you think of this?

#### Topic 5 Cooperation

We heard that people in Makwanpur work together in lots of different circumstances. When there are problems of money or of manpower, people rely on their neighbours and friends to help them. There is an expectation that if you are able to, you must help others. We heard that people share the things that they know with others – gossip and knowledge.

What do you think of this?

#### Topic 6 Context and problems

We heard that it is sometimes difficult to live in Makwanpur but it has its advantages and disadvantages. People here are poor and work hard, and there are different problems of water supply, landslide, education and drinking of alcohol. Caste and gender are issues that often define how people interact with each other.

What do you think of this?

Thank you very much for your time, it is very interesting to hear your opinions.

